

# CICADA BUZZ

## Jan Pryor

### Guest Speaker at the May BBQ

Jan Pryor, our guest speaker at May's BBQ, is a Central Coast Visual Arts High School teacher. She is a member of Northlakes Toukley Rotary Club and she was recently appointed RAWCS 9685 District Chair.

Jan joined us to talk about "The Didi Foundation", an Australian registered charity she established in 2012. In the same year she established an NGO in Nepal, "Didi Foundation Nepal". "Didi" means sister and the foundation implements programs to empower women and children in Nepal, to assist them in developing sustainable futures. These programs include:



#### Didi Headquarters in Kathmandu

- Maternal and child health programs for the disadvantaged women
- Sustainable life skill programs that are designed to empower women to assist in creating sustainable futures.

Didi Headquarters runs:

- o Sewing School
- o Computer courses
- o Women's Literacy
- o Manufacture of Re-usable Sanitary Kits (for school girls)

**Stop Press** - The manufacture of sanitary kits has ceased production and the foundation is looking for \$3,000 to run the program for one year which is tax deductible. The kits are given to young girls to enable them to go to school every day of the month.

- o Women's Co-operative to assist in income generation

#### Collaborative Projects with the Nepalese Government

(short course programs)

- Traditional Weaving Course
- Workplace preparation
- Beauticians course

#### Outreach Programs

- o Re-Built an earthquake damaged school in Ramechhap Nepal
- o Support Sindhuli Deaf School with donations in kind

Jan had an amazing story to tell about her struggle of survival during the April, 2015 Nepalese earthquake where Jan and her two friends were listed as missing for five days.

She takes enormous pride in her small 'grass roots' charity and with the support of generous donors is able to 'Create a Future and Change a Destiny' by empowering women and children with sustainable futures in Nepal.

Find out more information about The Didi Foundation Inc, on facebook. All donations are tax deductible.



# State CICADA Associations

## New South Wales

### CICADA AUSTRALIA INC.

Secretary: Judy Cassell  
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## ACT

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## Hook Up Online And Share Your News

Please visit us at [www.cicada.org.au](http://www.cicada.org.au)  
Or our Facebook page Cicada Australia Inc.  
Darwin friends now have their own Facebook page Cicada Northern Territory

If you would prefer to receive this newsletter by email, please send your details to [suewalters@cicada.org.au](mailto:suewalters@cicada.org.au)

Donations over \$2 to CICADA are tax-deductible.

CICADA Australia Inc. thanks Cochlear Ltd. for supporting the design, printing and distribution of this newsletter.

# Presidents Message



## MAY 2016

The Honourable John Howard, Australia's 35th Prime Minister and Patron of the Deafness Forum, delivered the Libby Harrick's Memorial Oration at the 9TH National Deafness Sector Summit (see report in this issue). Mr Howard spoke about his own life experience of hearing loss and described deafness as "a deeply personal thing for those who suffer from it". For those of us who DO have hearing loss, this is exactly that...Deeply personal.

Communication is what connects us in life and to be in a position where you cannot truly relate to others can be frustrating and with it, feelings of isolation and lack of confidence. It's important to remember that life is changing all the time and not to get too overwhelmed when doubts start to creep in. Our own expectations of ourselves sometimes create disappointment if we don't accept that change is a part of life...whether we like it or not!! We are here to learn and sometimes the lessons are not easy.

Talking to others can change our perspective and encourage us. This is what we do at CICADA. Hearing loss can be difficult to accept but cochlear implants can certainly help to connect you to the world again.

## 9th NATIONAL DEAFNESS SECTOR SUMMIT

Deafness Forum of Australia presented the 9th National Deafness Sector Summit at the Australian Hearing Hub, Macquarie University on 7th May 2016. This brought together a wonderful range of representatives from Deaf, Deaf/blind and hearing impaired organisations, professionals and volunteers to discuss current issues and present proposals for the future. Amongst the hearing impaired, there is still a lot of uncertainty about whether the National Disability Insurance Scheme (NDIS) will adequately provide

hearing assistance in the future, however the government is reassuring us that no-one will miss out on services. Senator Doug Cameron spoke passionately about lobbying to keep Australian Hearing in the public domain.

President of the Deaf Society and recently appointed Disability Discrimination Commissioner, Alastair McEwin, is deaf and communicates in AUSLAN. One of his priorities will be to see the successful implementation of the NDIS so there can be more equity in education, employment and social opportunities across all types of disability. Alastair feels honoured to hold this advocacy position and is encouraged by the fact that deaf professionals are increasingly being employed in the law, management and executive positions in both deaf and mainstream organisations.

Full access to communication was a pertinent topic at the Summit, with Sven Topp advocating to "narrow the gap between the various groups of deaf/blind individuals" and AUSLAN users speaking out for more awareness of their needs in this regard. Availability of technology to augment hearing may not be their prime concern, compared to those who use hearing aids and cochlear implants. Rather, by presenting their case, they hope to get more access to captioning (on TV and online or educational video), AUSLAN translating services, fully accessible Internet for visually impaired, improvements in haptic communication (touch).

Gary Kerridge, from Deaf Victoria who works in mental health, says that there is a lot of complaining, that the system (the Disability Discrimination Act) requires us to constantly complain and this is very stressful for those whose needs seem to be disregarded. Steve Williamson, CEO of Deafness Forum says that rather than complaining, the DF is trying to present the issues clearly, with some workable ideas for solutions.

Paul Brant, Manager of Recruitment Services for Australian Hearing, is working to increase employment of Aboriginal and Torres Strait islanders. Basil Turner, volunteer with the LinkAGE Program, a hearing helper program, spoke about improving hearing assistance to older Australians, especially those in care who are dependent on nursing staff to manage their hearing devices. Three-quarters of aged care recipients suffer some degree of hearing loss. Even a slight to moderate hearing impairment can inhibit social interaction, reducing quality of life, increasing depression and dementia.

Transcripts from the Summit should now be available on the Deafness Forum website. Please do have a look as there is some very good information.

# VIKTORIJA McDONELL on AURAL REHABILITATION

## Our second guest speaker at our May BBQ day

Viktorija is a rehabilitation specialist at Cochlear Ltd and over many years has worked on CI programs in Australia and Eastern Europe to help recipients make the most of their hearing. Vikki is also the mother of Holly McDonell, the first child implanted in the Sydney implant program in 1987, so Vikki has first-hand knowledge of the skills and practise that are required to help those with a cochlear implant. Holly has done exceptionally well, graduating from University with Honours in Law and currently working as General Counsel for a large company, so she is certainly using her listening skills to a maximum every day.

Vikki presented a "Telephone with Confidence" program that Cochlear Ltd is currently developing. Clients can build up their listening skills on the phone at their own pace, practicing at different levels of



tempo and complexity, including various accents and in noise.

Vikki also recommended Aural Rehabilitation exercises. There is a wide choice available on the Cochlear website: <http://www.cochlear.com/wps/wcm/connect/au/home/support/rehabilitation-resources/useful-websites>

Many thanks to our guest speakers for their enjoyable presentations.



## Music to mend memories in the minds of dementia patients

4 April, 2016



Professor Bill Thompson and Dr Ameer Baird

Two Macquarie researchers, Professor Bill Thompson and Dr Ameer Baird, both from the Department of Psychology at Macquarie University and the ARC Centre of Excellence in Cognition and its Disorders, have begun looking at how music can help people with dementia by comparing how personal memories are evoked with music and other stimuli.

Throughout his career, Professor Thompson has investigated the power of music over the human brain, looking at the healing effects it can have on the mind through case studies and his own research. "I enjoy learning about and delving into some of the most subtle and complex aspects of the relation between music, thought, and feeling, yielding an exciting body of knowledge that we call 'music perception and cognition,'" Professor Thompson said.

Music has previously been used to treat an array of cognitive conditions including autism, ringing in the ears (tinnitus), impaired motor skills or difficulty speaking (aphasia) after stroke. In one famous case, an 11-year old stroke patient called Laurel learnt to speak again through singing – called melodic intonation therapy – which trained her brain to use new pathways to produce speech.

Dr Baird, a clinical neuropsychologist, has previously researched the link between music and memory in persons with brain injury or dementia. Her recently published book chapter explores the effects of music on persons with dementia and how music can potentially be used as a tool to treat symptoms of the condition. "There is increasing evidence that shows music can have positive effects on persons with dementia. Even in the late or severe stages of dementia when verbal communication may have ceased, a person's ability to respond to music is potentially preserved," Dr Baird explained.

More recently, Dr Baird has been awarded a four year NHMRC-ARC Dementia Research Development Fellowship with Professor Thompson as her mentor, allowing the two to combine their expertise and tackle a very specific question: how music can help dementia patients recall their past and whether it can help to reaffirm self identity?

"We really want to explore whether music can aid dementia patients with their autobiographical memory, which is very important when it comes to self identity" Professor Thompson said.

"In particular, by comparing how personal memories are stimulated by music versus other stimuli, such as photos or objects, we will be able to gain more insight into the relationship between music, autobiographical memory and self identity over time."

They will investigate this issue in persons with different types of dementia, mild cognitive impairment and healthy elderly persons.

"Music is easily accessible and can be an effective way to maximise well being, which is crucial given that there is currently no cure for dementia" Dr Baird concluded.

# Deafness and Music Felicity Bleckly



I used to get so frustrated when a person found out I was a musician before I went deaf. So many people would say 'Beethoven was deaf' implying that deafness wasn't an excuse to stop being a musician and, because I had, there was something lacking in me.

Hearing is necessary for the enjoyment of music and as my hearing declined I heard fewer notes on the piano. I could measure my hearing loss by playing down the piano until I came to a note I could still hear until eventually I could hear none of them. And that's the way it remained for about 15 to 20 years.

When I first enquired about a Cochlear Implant back in 1995 I was told I would probably understand speech, although there were no promises, and while I might hear the sounds in music it would still not be pleasant. So imagine my joy when at switch on I understood speech instantly without the need for lip reading. It sounded funny because my left ear was my worst ear and it had not heard sound for about 30 years.

A few months later I tried listening to music that I knew but it was at first just a cacophony of sounds all rolling around together. So disappointing, but I decided not to give up. It was only a few days later when I tried again and this time it all came together and I recognised the music I was listening to. A moment of pure joy, which allowed me to believe I might play the piano again.

Fast forward to 2015. Without much hope I submitted a video of me playing the piano to the Beats of Cochlea Music Festival <http://festival.ifps.org.pl/en/> It was an amazing surprise when I was chosen to fly to Poland to participate in the Gala Concert. An amazing experience and it reawakened my passion for the piano. I am now taking lessons and studying towards Grade 8.

Does music sound the way I want it? Almost all the time a resounding yes! Some days my hearing is off a little and it doesn't sound quite right, but the more I play the better it sounds. At first scales

didn't sound as if they ended but the more I play them and once I worked out the fingering, my fingers and my brain worked in tandem and then they sounded right. I would still like a small tweak in quality in my right ear but my left ear is terrific. Together the sound is so close to what I remember.

The 2016 festival will be held in July in Poland. You can link to my performance at [www.c-a-network.com](http://www.c-a-network.com) then choose stories and find Felicity.

## Shirley Ackehurst Celebrates her 30th Anniversary

### Denied a career in nursing, Shirley became a medical pioneer instead



Shirley with her grandson

When Shirley Ackehurst was a little girl, she dreamed of becoming a nurse. But when her dream was shattered after a bout of mumps left her deaf, she could never have imagined the part she would later play as an Australian medical pioneer.

Shirley is 74. A mother and grandmother who loves working in her garden. She's also a medical pioneer whose story is one of perseverance, loss, heartbreak and triumph that she relays with such poignancy, humour and courage it is impossible not to be moved and inspired by her.

But in 1956 Shirley was an 11-year-old girl who contracted mumps. It changed her world forever. "I didn't realise I had lost my hearing at first," she recalls. "When I went back to school, everyone seemed to be mumbling and I couldn't understand them. I thought something had happened to everyone else. Not for one minute did I think something had happened to me."

The adaptability of childhood meant her deafness remained undetected for several years. "Although I didn't realise it, I started to lip read straight away and no-one noticed that I couldn't hear very well," Shirley says. "I still passed my tests and kept up with my school work."

As a country kid from Corop West in

Victoria, Shirley attended a boarding school for two years. It was when she returned home that her parents began to notice that she didn't answer if she wasn't looking at them. "They decided to take me to a hearing specialist and I believe we were all shocked when he told us I was very deaf and I had only been coping by lip reading," she recalls.

Then came the blow. For as long as Shirley could remember she had wanted to be a nurse. "I was due to have a medical exam after I won a Nursing Bursary. When the doctor tested my hearing, of course he found out how deaf I was and my treasured bursary was cancelled. I was shattered."

Shirley was now very shy, self-conscious and began to feel isolated, lonely and miserable. "Social outings were fraught because I couldn't lip read in poor light in the evening," she says. "I started to hide my deafness and pretended I could hear, which led to all kinds of misunderstandings and even more embarrassment."

Shirley received her first hearing aid at 15. "It was large and heavy, like a metal cigarette box," she recalls. "I wouldn't wear it, partly because it didn't help at all and partly because I felt too ashamed to wear it. After I was married I tried out a more modern aid and it still did not help me to hear much better. I eventually gave up on it as my hearing gradually got worse."

Fast forward 30 years and Shirley found herself entering the medical world – not as a nurse, but as a pioneer. A Cochlear™ Implant clinic opened at Flinders Medical Centre in South Australia in 1985, and Shirley couldn't wait to get a referral. "I was unable to hear my daughters' and husband's voices by now, so this information about the implant gave me hope," she says.

On 15 April 1986, Shirley (then 44) became South Australia's first Cochlear™ Implant recipient.

That first sound processor was a heavy metal container, a little larger than a packet of cigarettes that Shirley wore on a belt. A far cry from the small, light, unobtrusive Cochlear™ Nucleus® 6 Sound Processor she wears behind her ear today. But it gave her the gift of sound.

"It wasn't until I arrived home and I heard my footsteps on our polished wooden floors and that I felt very excited," she recalls. "The sound anchored me back into the hearing world. My hearing came in slowly and I remember on the third morning after switch-on I was buttering the toast for breakfast and I could hear the crackling sound that makes. Small everyday sounds filled me with so much

excitement. The environmental sounds were the ones I loved most in those early days, rain on the roof, the birdcalls, the click of my little dog's toenails on the polished wooden floor."

As South Australia's first Cochlear implant recipient, Shirley was asked to do a lot of public speaking about her experience. "I would have run a mile from this before my implant," she says. "In fact, I'd never made a speech in my life before. I wrote a book, Broken Silence and I went on an author's tour of Adelaide, Melbourne and Sydney with numerous radio, newspaper and TV interviews including the Ray Martin Show. I volunteered for committees and helped to start up a support group, the Cochlear Implant Club and Advisory Association, South Australia. With my friend Rhonda Smith (another implant recipient), we spoke to people before their implants, visited them in hospital and supported them in the early weeks after their implant. I also helped to raise funds for Better Hearing Australia."

Shirley says her life would have been very different during the past 30 years if she did not have her Cochlear Implant. "I would have been isolated and lonely," she says. "I would have avoided social situations. I would have existed in my own silent world."

She says the greatest gift her implant has given her is the ease of communication with family and friends, as well as the sounds of nature. "One of my greatest joys is to have my breakfast outside every morning and listen to the birds," Shirley says. "It has given me the joy of hearing the birds, rain on the roof, wind in the trees and music. It has given me confidence and self-worth. It has anchored me back in the real world. It has made my life warm and happy."

But for Shirley the most beautiful sounds of all are those of her grandchildren's voices. "My youngest grandson, Harrison, who is three years old, inspects my processor every time I see him and tests it out by saying different words in my ear. He is quite fascinated with it."

## Laughter is the Best Medicine

Three retirees with hearing problems were playing golf

"Windy, isn't it?"

No, it's Thursday"

"Me too, lets have a beer"

## NSW Support Groups

### Illawarra

What a great day as Cicada Illawarra hosted its first Windang/Lake Illawarra Picnic on 17th April. We continue to be blessed with the weather for our outings

It was just fantastic to catch up with friends and to also meet some new faces. A highlight of the day was Frances's fabulous birthday cake, provided by her daughter

With a gathering of 30 plus, Bob and Robert continued to impress all with yet another quality BBQ – thanks!



### This is Rob's story.

Rob was born in 1941 profoundly deaf owing to his Mum having Rubella while pregnant. Life was not easy for Rob through his school years. Hearing aids were much bigger and the children would make fun of him.

I met Rob in 1966 and in 1969 we were married. Rob had difficulty hearing in crowds and lacked confidence. In 2011 he was told he was suitable for a cochlear implant. Being a little apprehensive we went to a couple of Illawarra social BBQS. Everyone that had the implant was very positive.

In August 2011 Rob had his implant. Three weeks later after being switched on we were driving home when Rob said, "Something is wrong. I can hear a click click noise." He was hearing the car blinkers. Fast forward nearly five years and Rob is a different man. He is so much more confident, goes out much more, plays bowls, the TV is turned down. It has been life changing for him.

He chooses not to have the other ear done, as he is happy with the implant in one ear and hearing aid in the other. We must thank Faye Yarroll, Bob Ross and David Romanowski for all their support.

Dianne Deller

The trial location at Windang/Lake Illawarra proved to be popular. Spacious shelters, plenty of parking and ease of access to amenities being appreciated. Given the positive feedback, this location will be added into the rotations for future Illawarra events.

If you know of anyone else in the Illawarra Region that would like to come and join the group then don't forget to spread the word.

Next event is on Sunday 26th June at Illawarra Live Steamers. For more information please contact David Romanowski.

Mobile: 0432 715 691

Email: dr930@unowmail.edu.au



### The Escapees – "young adults" with cochlear implants & friends

February saw us at Wet'n'Wild Sydney. A cloudy morning gave way to a warm & hot day, excellent for the water park. Variety & fun was the norm. From a waddle in the shallow beach to the challenging and scary rides. What a day!

A comment from an anonymous, brave female escapee

"An awesome time at Wet'n'Wild. With the majority of us not wearing cochlear devices on the wet rides, others in the group couldn't hear me screaming all the way down!!" I need to publicly thank Wet'n'Wild for the great discount afforded to our group, it was really appreciated.

Our April outing and a change of pace was in order. We explored Darling Harbour, Barangaroo & Circular Quay. Can report no escapees were lost and it was great to catch up with everyone. A well-deserved lunch and coffee was in order after 3 hours roaming around Sydney Harbour. Special thanks to Tia who led our "walkabout"

The Escapees have bimonthly outings in Sydney that revolve around having fun while spending time together! This group organises and communicates the events from a private Facebook group. If you would like to know more then please contact David Romanowski (Email: dr930@uowmail.edu.au Mobile: 0432 715 691 or directly on Facebook)



## Northern Rivers

The Northern Rivers Cicada group had a great morning when they met on 26th May. A mixed bunch of relatively new implantees, ranging from three years since activation to four weeks, together with people on the waiting list, spouses and those exploring their options.

There were lots of interesting and funny testimonies from all who attended. As well, there were concerns and questions raised by those who are exploring their options and those who are about to begin their cochlear implant journey.

All in all, it was a fun filled and enlightening meeting.

Many thanks to the Seacoast Church who has generously offered their new conference room for the meetings of the group.

For information about the group and their meeting dates contact: Sheliya Van Buggenum meerschamvale@yahoo.com



## Western Sydney

Western Sydney Group had a cold start to their gathering on Sunday 29th May, but it soon warmed up when the sun came out. There was a good turnout, including some first timers.

The next BBQ will be held on 21st August 2016 starting 10.30 in the Rosella picnic Area, Nurragingy Reserve, Knox Road, Doonside. In wet weather, all the area is undercover with play area for kids nearby. This will be followed by the last BBQ of the year on November 27th 2016.

You can contact Sean and Margaret Sewell on Mobile +614 2521 5654 or 041 5205 877  
Judy Tutty – Co-coordinator 043 704 9452 for more information.

## Cicada Functions at Gladesville

The year is rushing by, but there are still a few functions to go for 2016.

BBQ's are to be held on 14th August and 6th November (AGM)

Morning Teas on 7th July, 14th August, 1st September and 6th October

Information can also be checked on the Cicada Website [www.cicada.org.au](http://www.cicada.org.au) or by contacting the secretary, Judy Cassell [jcassell6@bigpond.com](mailto:jcassell6@bigpond.com)

## Housekeeping

### Change of Address

Cicada still receives many "Return to Sender" after each mailout. Don't forget, if you are planning to move, please send us your new contact details: by snail mail to Judy Cassell PO Box 5028, South Turramurra NSW 2074 or Email [judycassell6@bigpond.com](mailto:judycassell6@bigpond.com)

### Raffle

Cicada will be running its annual raffle later in the year. If you would prefer not to receive raffle tickets in the mail, please contact Judy Cassell – contact details as above – or Sue Walters: [suewalters@cicada.org.au](mailto:suewalters@cicada.org.au). Those members who have previously let us know, there is no need to let us know again, as the information has been entered on our database. A number of people have indicated that they would prefer to give a donation, if this is your preference, please let us know.

## Helpers

Cicada operates with a small committee and a group of dedicated helpers. If you would be interested in becoming more involved with Cicada, you would be welcomed with open arms. Contact secretary Judy Cassell on the above email address. Below are some photos of committee members/helpers, taken at our May BBQ.



Maria Keegan and BBQ chief Johnny Boyce



Caterer extraordinaire and Treasurer Chrissy Boyce and committee member Alan Jones



Peter Keegan



Roma Wood and Robyn Jones

## Laughter is the Best Medicine

A man was telling his neighbor "I just bought a new hearing aid. It cost me \$8,000 dollars, but it's state of the art. It's perfect."

"Really," answered the neighbor. "What kind is it?"

"Twelve thirty"

# From Steve Williams Chief Executive Deafness Forum

## Replacement speech processors for pensioners aged over 26 years

*Addressing the inequity of Age and Disability pensioners who are denied Government support for replacement cochlear speech processors.*

Age and Disability Pensioners who have cochlear implants and are eligible for the Australian Government's Hearing Services Program are denied the appropriate, reliable technology through the Government which they depend on for social inclusion, productivity, independence and quality of life.

These "Eligible Persons" under the Hearing Services Administration Act 1997, are not provided with replacement cochlear speech processors. However, people who use hearing aids as their means of amplification are (quite correctly) provided with replacements and upgrades to their hearing aids as required.

This inconsistency impacts the most significantly impaired and financially vulnerable cochlear implant recipient group. It can be readily addressed at little cost to Government.

To its credit, the Government does provide replacement and upgraded cochlear speech processors for people under the age of 26.

Our understanding is the planned transfer of parts of the Australian Government's Hearing Services Program to the National Disability Insurance Scheme will resolve the matter for people who are eligible to enter the Scheme. This may take several years to be put in place.



*Break the Sound Barrier* is uniting our entire sector for a common cause - to make hearing a national priority.

Hearing is not one of Australia's national health priorities. We do not have the adequate investment in services and research we need. It also means there is not a focus on community education. It's a barrier that is preventing too many Australians from reaching their potential.

The campaign was launched recently and has a new website and Facebook page and even a video. Its aim is to tell our stories and share our experiences to get hearing on the national agenda. The long term goal is for state and the federal governments agreeing to make hearing Australia's 10th national health priority.

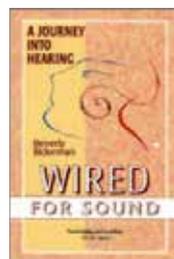
We've also put together a six point election plan that campaign supporters will be asking all parties to support ahead of the election to show they're listening. It's called *Be Heard this election*. We've already started to be heard in the media and this is only the beginning.

## Be part of the movement to Break the Sound Barrier!

1. Social media is a powerful tool. Like and share our Facebook page and Twitter. Use the #soundbarrier hashtag when posting and tweeting about hearing health and wellbeing.
2. Show your support for the campaign at: [www.breakthesoundbarrier.org.au](http://www.breakthesoundbarrier.org.au). The more people who sign up to the campaign, the greater chance of being heard this election, so why not send them an email asking them to join your organisation as a Break the Sound Barrier supporter?

## Books

### Wired for Sound: A Journey into Hearing by Bev Biderman 2016 second edition



Bev's memoir in 1998 of learning to hear with a cochlear implant is the basis for an opera "TMIE, on the threshold of the outside world" which premiered in English in Portugal in February 2016. The intriguing TMIE is the name of a gene involved in hearing and deafness.

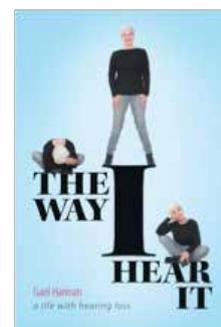
An updated version of her 1998 book is now available as an e-book, in the USA and Bev's home country Canada from Amazon and in this country from Amazon Australia.

For those who have read her 1998 book the main new feature is the chapter "Postscript to the 2016 Edition". This covers her second implant and replacement of her first implant, along with new and revised material relating to most of the other chapters such as her history, technological progress, social progress including changes in the signing deaf attitudes.

For those who have not read her 1998 book, these seven chapters provide an emotional, entertaining, thorough and well-researched account that, even if somewhat dated, is still a valuable insight into all aspects of a cochlear implant journey. CICADA members, including this reviewer who has been profoundly deaf even longer than Bev and like her has a university background, will find much that is familiar to them and some that is different across each of the phases: life as a deaf person, pre-implant considerations; post-implant experiences.

The first edition also had a wide impact on professionals in the hearing field and outside it (for example the late Oliver Sacks called it "a beautiful account full of wonder and surprises"), on politicians and the interested public internationally. This second edition will hopefully continue to impact more widely especially given that even in 2016 only a small percentage of those who could benefit from cochlear implants actually have one.

### The Way I Hear It: A Life with Hearing Loss By Gael Hannan



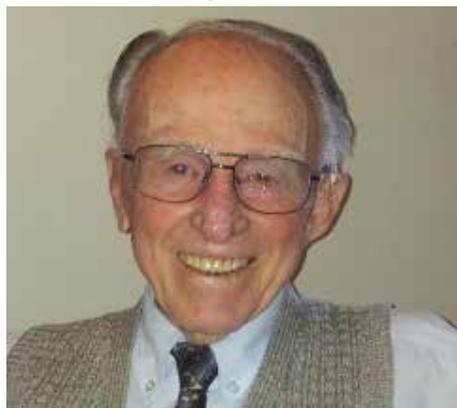
In *The Way I Hear It*, Gael Hannan explodes one myth after another in a witty and insightful journey into life with hearing loss at every age. Blending personal stories with practical strategies, Gael shines a light onto a world of communication challenges: a marriage proposal without hearing aids in, pillow talk and other relationships, raising a child, going to the movies, dining out, ordering at the drive-thru, in the classroom, on the job and hearing technology.

Part memoir, part survival guide, *The Way I Hear It* offers tips for effective communication, poetic reflections, and heart-warming stories from people she has met in her workshops and at conferences throughout North America. Gael's humorous stories are backed by hearing loss research, and she offers advice on how to bridge the gap between consumer and professional in order to get the best possible hearing health care.

Published May 28th 2015

# Edward John Lees ROBERTS

Cochlear Implant Journey,  
2011 onwards, Born 1920



I lost my hearing when I was 24 years of age and in the early sixties Dr Alan Bryson specialist operated on my left ear in what is known as "Fenestration". Unfortunately I only received enough benefit to hear quite well with a hearing aid. The right ear was operated on some 12 months later but to my disappointment my hearing was not improved. So from the early 1960's to October 2011 I was dependant on my hearing aids and lip reading. In May 2011 I suddenly lost hearing completely.

My Audiologist at Australian Hearing at Chatswood made the appointment for me to attend the Gladesville Cochlear clinic. The Audiologist Monica Bray gave me every encouragement to go ahead with a Cochlear ear implant. I had visited the Cochlear factory one year previous with a church seniors group so I understood the benefit I should receive from the implant. After all the preliminary tests and x-rays I was referred to Professor Melville Da Cruz at Westmead Private Hospital for the surgery on the 4th October 2011 for the left ear implant as it was considered the better ear to do. Under Professor Da Cruz expertise and skill the implant was successful and my new Audiologist Samantha was surprised at the quick results for hearing over the next twelve months of mapping the processor. I was talking on the telephone within 6 months.

Unfortunately the muscle used to fill the cavities left by the original Fenestration operation broke down and my ear started weeping and another operation was necessary to fill the hole which had appeared exposing the electrodes of the implant. On-going infection caused skin breakdown and I had four skin grafts. These set backs were outweighed by the benefit I was receiving from the implant which still worked perfectly to give me my hearing.

In 2015 the implant suddenly stopped working and a coil protruded from my ear which was most unusual for this to

occur, no one had seen this before. I was devastated to lose my hearing again. With the support of the team and Professor Da Cruz the decision was made to remove the implant and instead implant a cochlear into the right ear on the 15th April 2015. The right ear was not considered to be as receptive as the left ear however I had worn a hearing aid. Now twelve months on with the new Nucleus 6 Processor I am hearing every bit as good as I was with the left cochlear if not better. I was using the telephone in less than six months.

My life has always been socially active since arriving here from Wales when I was 15 years old and worked in the steel mills at Newcastle while taking up amateur boxing, eventually winning the Fly weight Championship of Australia in 1939. I was involved in ministry with the Baptist Church in Islington Newcastle and felt a Spiritual call to take up the ministry of the Gospel full time. I had met and married my beautiful wife Jean during this time and after a pastorate at Cessnock church we came to Sydney to settle and raise our two children. I worked for the Australian Gas Company for thirty nine years in various trade roles finally as the First aid officer retiring 1984. While working full time I was still involved with pastoral ministries with the Africa Inland Missionary group.

During retirement I lead a very busy life as a member of Eastwood Baptist Church, family activities and eleven great grandchildren and looking after my wife. For the last eighteen months I have been visiting her in the nursing home almost every day. I live independently, kept busy with all the "domestic duties" and with the help of my family lead a very active life.

Yes, I have had set backs post first Cochlear implant however it still has improved my quality of life, hearing birds chirp and clocks ticking, using the telephone and not relying on lip reading all the time. I cannot thank the SCIC team at Gladesville and the Westmead Private Hospital Cochlear implant team enough for their dedication and skill to this great invention. I would recommend to any deaf person to investigate if the Cochlear is right for them, no matter how old you are. I am now ninety six!

## Research

### Would you like to be involved?

**Study 1** Listening with a cochlear implant can be challenging, particularly in noisy environments. Different types of auditory training programs exist, but it is still unknown why everyone does not benefit from it and how we can better target the training for each person.

We seek to recruit adult cochlear implant users to help us evaluate the efficacy of computer-based training programs as part of a research collaboration between Macquarie University and SCIC Cochlear

Implant Program, an RIDBC service.

If you choose to participate, you would compare two different types of computer-based training programs at home at different times. Each training would last 6 weeks and will be followed by a 3 month (no training) interval, to make sure the benefits of training are maintained. You will be asked to come to Macquarie University for 7 testing sessions (Australian Hearing Hub, 16 University Avenue, Macquarie University). During these, we will measure how training affects your ability to understand speech, your memory skills and your brain activity. You will be reimbursed for your time and travel expenses at the end of each testing session.

You can withdraw from the study at any time without having to give a reason.

Study	Comparison of training programs for adult CI users
Who can participate	<ul style="list-style-type: none"><li>- Older than 18 years</li><li>- English speakers</li><li>- Deafness in both ears acquired after age 4</li><li>- More than 1 year of CI experience</li><li>- Who have access to a Windows computer with internet</li></ul>

If interested, contact: Mariana Reis  
<http://www.scic.org.au/our-clinic/research-at-scic/recruiting-research-participants/>

**Study 2** We are currently recruiting participants to be involved in a research study looking at "The Effect of Stimulation Rate and Number of Maxima on Music Perception and Appreciation for Adult CI Recipients". This study is part of a Masters of Clinical Audiology thesis being conducted by Sebastian Ryan at Macquarie University.

The aim is to see if we can improve music listening, and/or speech perception in noise, by changing different settings in a CI program (MAP). It is hoped that these results will provide more information for your audiologist, as well as the CI manufacturers on what can be done to try and improve the CI.

We would need you to attend 2 sessions to be held at Cochlear Headquarters or the Australian Hearing Hub (both at Macquarie University). Each session will take no more than 2 hours, and can be arranged at a time to suit you (7am to 7pm Monday to Friday, or Saturday morning till 1pm). We will be able to reimburse you with \$20 per session.

If you have any questions about the study, or wish to participate, please feel free to get in touch with the details listed below. Sebastian Ryan – Masters of Audiology student

Email: Sebastian.ryan@students.mq.edu.au  
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