We celebrated International Cochlear Implant Day on Sunday 24th February as our first BBQ event for 2019 (though the official date is 25th February). It was a fantastic gathering of almost 200 people. Cochlear Ltd assisted with their sponsorship for this event, their cupcakes, the Coffee Cart and DARE the wonderful magician who roved around entertaining us with astounding tricks. RIDBC/SCIC staff came to the party with their valued help and of course, CICADA would like to thank SCIC for the continued use of the premises at Gladesville, which are so well suited to holding these gatherings. We had a number of other stalls to really add to our day and I am grateful to those who attended to share their resources- MEDEL implant company, Deaf Society, Hear For You, Pauline Findlay with her book “Can You Feel It?” about a teenage girl with hearing loss, Andrew Stewart with his new business HEARING CONNECTIONS.

We began with some presentations in the Conference Room. Polly Templeton was there to do the live captions and Steve Pascoe generously offered his services to LIVE STREAM for us.

This was a FIRST for CICADA !! Steve captured the live presentation, which can be viewed on this link: https://vimeopro.com/pascoeberry/cicada-international-cochlear-implant-day

The link will be available on the CICADA website so you can go to www.cicada.org.au and click on it to watch the video with the captions. It was captured LIVE so there are a few typos in the captions that cannot be corrected.

Associate Professor Cathy Birman spoke about the services of SCIC (see brief summary in this issue) and Cochlear Ltd introduced us to Kunal Amalean from Sri Lanka, who has just celebrated 20 years with his implant, by Prof Gibson in Sri Lanka when he was 9 years old. Kunal came to Sydney a couple of months ago to have bilateral surgery so he is still adjusting to the sound from his new implant. See a brief summary of his presentation in this issue (and watch the video!)
Presidents Message

FEBRUARY 2019

Going back to our AGM last year, 11 November 2018, was the Centenary of the Armistice that ended World War I. Almost 62,000 Australians died in service to our nation during the war 1914-18. As a mark of respect I read part of Laurence Binyon’s poem ‘For the fallen’ and we had a minute’s silence.

There are many people to thank for helping us through the year and providing general support to those with profound hearing loss.

CICADA groups in WA, Darwin, Queensland and New South Wales who are actively keeping groups going, our Illawarra south coast group, Western Sydney and Lismore support groups all seem to have found their place, being there for recipients. Sydney CICADA committee provided a nice round of social events in 2018, continuing our morning teas and barbecue days with some interesting presentations. It is encouraging to see an average of 20 to 35 at morning teas and 60 or more at barbecue days.

Potential cochlear implant recipients who come along to make enquiries can benefit from meeting and discussing the difference an implant can make to one’s life. It is very reassuring to new recipients as well who might be feeling that their progress is not what they hoped for or perhaps need a bit of encouragement and advice on how to improve their listening skills or how to manage their new equipment to best advantage.

Anyone can start a new group. There is always a need for more!!

Aged care issues have been highlighted as a concern and we are liaising with other groups to see what we can do on practical terms to help cochlear implant recipients who live in care. We can all build awareness about cochlear implants by telling others how we hear.

Better Hearing Australia Canberra produce a hospital kit for general awareness of hearing loss. It’s available from: http://bhacanberra.org/patient-hospital-kit/

QUOTA Club Bowral some years ago put out a Hearing Helper, which is a series of small cards with basic information about hearing aids and cochlear implants. This is currently being updated.

Tanya Marie Silveira presented at our 2018 AGM on Music Therapy and how it helps with auditory rehabilitation. We all thoroughly enjoyed this talk and especially when she asked us to SING !!!! Tanya had so many good ideas and it was most encouraging to learn about different ways that music can be appreciated with a CI. See the report in this issue.

I’d like to thank my current CICADA committee who nominated me for the Order of Australia honours this year. It was such a lovely surprise to receive that. I am really touched that they thought of it. I often feel I am just fumbling my way along here trying to come up with ideas or some sort of new direction for CICADA. But without my team, the barbeque days, the morning teas and newsletter wouldn’t happen without our core group of committed members. We get good feedback from people who come along to our events. This is what keeps us going. CICADA is just a small part of something bigger but I know my CICADA committee have their heart in the job.
If you ask me what is the single biggest thing that has had an impact on me during the last two decades, I would say access to hearing and speech clarity.

At the age of nine, I spent seven months in Sydney with my Mum, who is here with me today, going through speech therapy classes. We also have my former speech therapist Lynne Richards from 20 years back. I used to be very stubborn and annoy these two very special ladies because at the time I didn't understand why speech therapy was so important. But now I'm extremely thankful to Lynne for being able to keep me entertained throughout the sessions.

After we went back to Colombo, Sri Lanka, where I spent the next ten years, the constant traffic noise, the humidity, the school classrooms all were not exactly equipped to support my hearing environment. It was very distracting, very noisy. Young teachers didn't quite understand how to handle a hearing impaired child.

One day I had a very interesting encounter in Dubai airport. You know the first processor that I had was the Nucleus Sprint body worn sound processor, it used to be strapped around my stomach and waist. As I was going through the security check the guards stopped me as they felt the processor. Immediately they started panicking and sent me to another room for a strip search. He asked me what the processor was. I said that it helps me hear and that without the processor I cannot hear. He said, 'I am so sorry, sir, I got scared because I thought it was a bomb'.

Now we are in 2019. I spent six years in Boston for my university studies and working in start-up companies, spent one and a half years in Indonesia and four years in Sri Lanka. I am now working in the family business in clothing manufacturing, more specifically in the IT and software part of the business.

I am now 29 and I decided to go for the bilateral cochlear implant on the left ear.

Mum and I came to Sydney in November last year, and we had the successful surgery on the left ear thanks to Cathy Birman. Now it has been exactly 12 weeks since the switch-on. I now have the latest Nucleus 7 sound processor. It is an incredible device that also has a Bluetooth streaming feature. Finally I'm able to have an app on the phone itself to control the volume and other settings rather than having a separate remote, separate cables and wires. They used to give me such a big headache back then.

The first impressions are amazing. Initially the first two weeks I could not hear the sounds as much. It had been 20 years since the left ear was used and it had been inactive. Luckily, before I had the cochlear implant on the right ear, I wore Phonak hearing aids on both ears when I was a little kid. So amazingly, the brain was able to pick up where the sound waves had previously left off.

The right cochlear implant has always been my strongest dominant ear. I use the right ear to rely on speech, language,
listening and communication. And I now use the left ear to help me with the sound localisation. Now each week I have grown to become a lot more comfortable with the new sounds on the left ear, although I still hear robotic static-like sounds which makes me feel like they come from a different planet.

Now I have noticed with the second implant whilst we have been driving around in Sydney for the last couple of weeks, that I am able to stay with my eyes focused on the road and am still able to participate in a conversation without looking, without turning my head. So I see this as a massive improvement.

It’s a wonderful feeling because I had thought that the right ear alone was enough, but apparently it wasn’t. Of course at that time I didn’t know any better. I now think of the right and the left ear as two buddy systems. The right needs the left to help to know where the sounds are coming from, and the left needs the right to help with speech and communication.

Now when I take the left ear off and focus on the right ear alone, still it feels like there is a massive vacuum, like something is missing. The sounds are not quite complete. So now I am fully equipped with two Nucleus 7 sound processors on both ears, it feels like it’s almost complete. It’s getting there; it’s almost complete.

I have had excellent support from SCIC. I will continue with my listening activities when I get back home. We have been here in Sydney for four months and we are heading back to Sri Lanka on Tuesday.

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**Laughter is the Best Medicine**  

_Pensioner’s Joke._

When old Fred went to join the local RSL, they asked him if he had a war record.

“Bloody oath I have,” he replied, “I’ve got Vera Lynn singing The White Cliffs of Dover.”

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**TANYA MARIE SILVEIRA**  

(AGM Nov 2018)

Tanya is a trained Music Therapist who works with children at RIDBC’s Matilda Rose Centre at Waverley and also privately. Music Therapy is research based. Therapists use music intentionally, and in Australia you need to be masters qualified and registered with the Music Therapy Association. Even though music therapy may look similar on the surface as entertainment and education, what informs the work is actually quite different.

Tanya showed some short videos of the work she does with the children to encourage them to speak and socialize together and it was lovely to see their response and interaction with the music. Cochlear implants process rhythm much more clearly than melodies, so we started with a clapping exercise. Half the room clapped one beat, then the rest clapped a different beat, then another beat was introduced, all sort of synchronized. Tanya explains that it’s a musical way to feel more relaxed, get to know each other… and we DID enjoy that. We all have the potential to sing. It doesn’t matter if you think you’re singing at pitch or not at pitch, engaging in singing is good for you at all levels. Tanya had us sing, “You are my sunshine, my only sunshine…” And I think most of us enjoyed that as well, because we were participating together in something that we might not usually do. Tanya says: “If there is one thing you take away from today’s presentation, let it be this – neuroplasticity. All of our brains have the ability to rewire themselves. Whether you like it or not, your brain can change. We can actually use music in hearing impairment to help rewire how we hear sound and how we produce sound.”

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**Dr Halit Sanli**  

Retired 2018

Halit is Turkish and grew up in Kusadasi, which is a port close to Ephesus. He attended the local school before gaining a scholarship to go to England for further studies. At the age of 17 years, he went to England and attended a finishing school in Paddington where he took his A levels after only one year of study. He then went to the University in Sheffield where studied electrical engineering and graduated BEng. He then achieved a master’s degree before spending two years on the North Sea oil rigs. Afterwards he went back to Sheffield University and finished his PhD on ‘electrical interference’.

Next he went to Malta and then to Libya where he worked for Colonel Gaddafi. Halit was working on the radar systems. Here, he met his wife, Lela who was working as a nurse. They married after a couple of months without informing either of their parents. Lela and Halit had two daughters in Libya, Esra and Jasmine. They enjoyed Libya but when the USA began to bomb Libya, they decided to leave and chose to come to Australia.

Halit was employed as part of the adult cochlear implant team at The Royal Prince Alfred Hospital in 1989. He was chosen by Dr Christopher Game. Christopher had a small team who were working to find the means to record the electrical evoked auditory brainstem potentials. Christopher designed an amazing biological amplifier which we still use today. At this time I hardly knew of Halit’s involvement.

Sadly Dr Christopher Game was forced to leave after an altercation with the then Dean of Medicine. Suddenly I began to know Halit. I remember, the first time we were able to record the electrical brainstem potentials and Halit went on to refine this so that we are probably the only group in the world who can test abnormal cochlear nerves using this technique.
Halit refined the recording of the electrical brainstem potentials, which are obtained after insertion of the cochlear implant so that the surgeon knows immediately if the implant is functioning properly and is correctly positioned. Halit has attended many more cochlear implant surgeries than any surgeon. He also tests the cochlear implant after the surgery if there are any problems. He has developed very sophisticated tests and his input has been immense. Many recipients owe a lot to him even if they were anaesthetised when he helped them!

Personally I consider that he is irreplaceable. He has been a wonderful colleague and a great friend.

Professor Bill Gibson

HEARING LOSS and HEARING SOLUTIONS
Guide Second Edition 2018


WHAT IS THIS GUIDE ABOUT?
There are 14 Chapters totalling some 90pp. It starts by summarising the numerous perceptions and misconceptions about hearing loss and the barriers to wider use of hearing solutions. Next we deal with what is involved in understanding hearing loss and potential solutions. Then follow descriptions of the wide variety of devices available and the ongoing technology advances. The focus of this second edition is on implantable devices for several reasons:

* hearing aids are long-established and well-known, with adequate overview and detailed comparative information available
* even the best-established of implantable devices - cochlear implants - are much less widely known, including across hearing professionals who do not specialise in implants, with a lack of independent, comparative, accessible information
* technological and surgical advances have made some implantable devices, much more capable and more widely applicable to different types and degrees of hearing loss

For example, cochlear implants were historically specific to individuals with profound bilateral hearing loss that hearing aids could not help. Now, CIs have not only become the standard procedure for restoring substantial hearing in the profoundly deaf, but candidacy extends to (i) moderate speech recognition with hearing aids (ii) significant residual hearing (iii) single-sided deafness (iv) no lower or upper age limits. The benefits people can receive from cochlear implants depend on a range of factors. One key indicator is the duration of the severe to profound hearing loss, such that early detection and intervention – both in children and adults – are crucial.

The last chapter, the longest in the Guide, summarises the latest technological developments, including those classified as Personal Sound Amplification Products (PSAP’S) rather than Hearing Aids. These are aimed at people with mild to moderate hearing loss. Importantly, the subsections therein on Bluetooth Connectivity and Mobile Phone Integration underline the amazing capabilities of hearing aids and implantable devices today.

PROFESSIONAL REACTIONS
The first and second editions have involved feedback and suggestions from numerous hearing professionals. Reactions have been very positive, for example: I really enjoyed reading the guide! It’s brilliant. So comprehensive, easy to read and relatable. I’m really impressed with the level of detail and can only imagine the hours you’ve spent researching new updates. The guide will positively impact so many people including professionals. I can see it being so useful for instance, at our hospital when new medics have a rotation in the Ear, Nose and Throat Department or when we have new Audiology students in our Department who are new to implant devices. Again - well done! It’s fantastic there’s people like you who are so pro-active and care enough to put in the hundreds of hours required to develop such a useful and thorough guide.

It is noted that the Guide does not include references because it is not intended as a scientific review or a comprehensive specialist text. Readers are welcome to follow up aspects of interest, find more detail, or update on the ongoing technology advances. We welcome feedback and suggestions. We would also like to gauge interest in proceeding to a print-ready version and printing at cost - please respond to info@cicada.org.au

Neville Lockhart, author of The Guide

WHO IS THIS GUIDE FOR?
Medical, audiological and other professionals in the hearing health field, along with a few of those who are hearing-impaired, their families and friends - who are interested and motivated to better understand the overall situation and their own options. About one-third of Australian adults have some degree of hearing loss. Only a minority of those who should have hearing aids do have them and use them, the majority do not. In respect of cochlear implants, even in advanced economies, less than 10% of those who would benefit have done so.
Brain Plasticity

What is it?

You may have heard that the brain is plastic. As you well know, the brain is not made of plastic... Neuroplasticity, or brain plasticity, refers to the brain’s ability to CHANGE throughout life. The human brain has the amazing ability to reorganize itself by forming new connections between brain cells... (Such a change occurs when a CI and CI processor is introduced. Your brain actually MOLDS to the CI processor input and eventually recognizes it as what it is.)

For the candidates and newbies out there: Your CI and processor (N6, Kanso, N7) will be/are just an artificial cochlea. All it does is capture sound signals. Your BRAIN is what ultimately does 99% of the actual work. Your CI is transmitting IOIOIOIOIOIO beeps that on their own are just beeps. It’s not transmitting the voice of your wife, or child. It’s not transmitting music. It’s electronic signals. YOUR BRAIN is the REAL TECHNOLOGY here. What starts as beep beep over time becomes whatever it is - be it your wife saying “I love you”, or your son saying, “Dad, I want a toy”, or an employer calling to say “We’d like to make you an offer” - and its because of your brain (brain plasticity). Your brain takes these electronic beeps and eventually adapts to them and learns how to interpret them and they become sound.

But it isn’t always instant. Some of you will have that “rockstar” activation, and you’ll rush to CI Town to share your joy! But the majority of you will not have that “rockstar” activation (meaning, you can HEAR right away), and you’ll do what I did - you’ll rush to CI Town to share your joy! You’ll be able to listen to the voice of your loved ones. You’ll be able to reconnect with friends.

Christopher Johnson

Review of Aqua+
By Anne Dernow
August 2018

I used the Aqua+ with my left N6 today for my first hydrotherapy session at the Lions Hydrotherapy pool at St George public hospital in Kogarah.

I pulled apart my processor and put it in the aqua sleeve - it took 2 attempts because the first attempt dislodged the battery, and I didn’t hear anything. Had to remove it all from the sleeve, reconnect the battery and put it back in the sleeve. This second attempt was successful.

The white clippy thing at the base of the sleeve didn’t look 100% watertight, it looked about 98%, and I wasn’t sure if it might allow water to get in or not. I hadn’t done it before so I figured it would be an experiment, regardless!

I then drove over to the pool from home.

I noticed that the car was quieter than usual - I figured this would be courtesy of the sleeve blocking some of the sound. I thought it might be a good idea to have a Hydro map put onto my processor at some stage, since I like to ‘set and forget’ and I realised I forgot my remote assistant and pressing buttons through the sleeve could get difficult.

My hair sounds VERY LOUD...

Once in the water, I could hear my therapist well. I did not fully submerge in the chlorinated water, but I did fall off a noodle and splash as I landed, and got the base of the sleeve wet. Didn’t think anything of it - I was too busy laughing!!

When I got home, I rinsed off the aqua, then pulled the aqua apart to retrieve the processor and wiped everything dry. I was pleasantly surprised to find the processor and battery had stayed dry, but the aqua base did feel slightly wet at the white clippy bit. I wiped it dry and the aqua and the coil went into the breeze box, and normal coil and earhook with same battery went back onto my head as per normal use.

We’ve got one happy person here!!

Support Groups

Illawarra

It was great to see those who turned up to our first 2019 Picnic for the year on Sunday 3rd February. What a day it was, sunny, warm and with a touch of wind.

The location certainly got very busy before lunchtime when unexpectedly 2 large buses full of international tourists arrived to admire the area.

Thank you to everyone who brought along food to share and thanks to Bill, Roy and Bob for the BBQ and providing tasty sausage sandwiches for all of us.
Announcement: I’ve listened to the feedback received from the members of the group and for the 27th October, the location will now be changed from the “Live Steamers” to the “Shellharbour Pool” site. I have attached the updated Flyer. Please help me in spreading the new update to your friends.

Feel free to reach out to me if you have any questions at all. David

Northern Rivers
Our end of year dinner was a very relaxed and social affair with heaps of delicious food, drinks and barista made coffee. It was great catching up with everyone and getting to know those who attended for the first time.

A big thank you to all who attended and to those who provided the delicious food and beverages. Our meetings would not be so successful without you. Also, many thanks to Seacoast Church for generously providing such a great venue for our group.

For Information contact
Moira Havard - moirak@bigpond.com
Alison Gron - 4926 8100

Understanding Musical Ear Syndrome

Jan 2019 Flagstaff Business News

Musical ear syndrome, also known as musical hallucinations or auditory hallucination, is more common than you might believe. It can cause enormous stress on the individual experiencing it. It is more likely to be a song or music without words but a few people have reported that they hear songs with words. One source estimates that auditory hallucinations affect more than five percent of the population! In cochlear implant patients, up to 22 percent of the implantees experienced the hallucinations before or after the implant. Musical ear syndrome can occur in people of all ages, with normal hearing, with or without traditional tinnitus and who are not experiencing sudden stress in their life. The majority of the people who have this condition have hearing loss. People may think the music is coming from a neighbour’s house or a car sitting outside the house. Although MES is not a “scary” disease, persistent hallucinations may disturb patients and affect their quality of life. Patients should be educated about the syndrome and firmly assured that they are not mentally ill. It is important to remember if the room is quiet then the music or sound you hear may be more noticeable.

More details on this interesting phenomenon on the Cicada website. www.cicada.org.au

Taree-Port Macquarie
For information and details of the groups activities please contact:
Robyn Herps - robynherps@westnet.com.au
Phone    SMS 0428 688 612.

Meetings continue to be held on the second Wednesday of EVEN months.

10th April   12th June   14th August   9th October   11th December

For Information contact
Moira Havard - moirak@bigpond.com
Alison Gron - 4926 8100

Western Sydney
Unfortunately, our previous meeting place at RIDBC Glenmore Park, is no longer available.

Until a more permanent place can be found, gatherings will be in the upstairs Café area of Penrith RSL, Tindale Street. There is plenty of street parking available, including for the disabled, with lifts or escalator to the upstairs area. 10am start. On the first Tuesday of the month.

For further details contact
Sean Sewell on Mobile SMS only
041 5205 877
Judy Tuty - Co-coordinator
043 704 9452

For Information contact
David Romanowski. Mobile: 0432 715 691
Email: dr930@uowmail.edu.au

Newcastle and Hunter Valley
We were fortunate to have had Joanna Hegazy from Cochlear Engagement Team at our December meeting, to discuss with us her role with Cochlear. Our members found this very helpful and Joanna was able to answer any concerns people had.

Western Sydney
For further information contact:-
Sheliya Van Buggenum - sheliyavan@yahoo.com or
Phone or Text 0422524284
OR Phone Lismore SCIC Office on 1300 658 981

Up coming dates for 2019:-
April 16th and June 27th

For further details contact
Diane and Christine

Marlene, Peter and Joanna Hegazy from Cochlear
Diane and Christine
Moira, Wendy (Area Manager of Hunter RIDBC) and Isabel

Understanding Musical Ear Syndrome

Musical ear syndrome, also known as musical hallucinations or auditory hallucination, is more common than you might believe. It can cause enormous stress on the individual experiencing it. It is more likely to be a song or music without words but a few people have reported that they hear songs with words. One source estimates that auditory hallucinations affect more than five percent of the population! In cochlear implant patients, up to 22 percent of the implantees experienced the hallucinations before or after the implant. Musical ear syndrome can occur in people of all ages, with normal hearing, with or without traditional tinnitus and who are not experiencing sudden stress in their life. The majority of the people who have this condition have hearing loss. People may think the music is coming from a neighbour’s house or a car sitting outside the house. Although MES is not a “scary” disease, persistent hallucinations may disturb patients and affect their quality of life. Patients should be educated about the syndrome and firmly assured that they are not mentally ill. It is important to remember if the room is quiet then the music or sound you hear may be more noticeable.

More details on this interesting phenomenon on the Cicada website. www.cicada.org.au
CICADA Australia Inc.

28th Annual General Meeting
Sunday 11th November

The Cicada AGM saw the following office bearers elected to the Cicada committee.

President  Sue Walters  
Secretary  Judy Cassell  
Treasurer  Chris Boyce  
Public Officer  Karen Cooper  
Andre Connelly  
Max Houterman  
Alan Jones  
Cecilia Kramar

CICADA would like to welcome new committee member Andre Connelly and to thank Anne Dernow, who stepped down from the committee, for her support and assistance over the last two years.

Many thanks to the 2018 committee members, together with unofficial members, John Boyce, Robyn Jones and Mary Houterman, plus the small band of volunteers who assist with the setting up and dismantling of tables and chairs and the secondhand bookstore at our functions, as well as helping with the food, mail-out of fliers and newsletters.

Cicada’s Annual Raffle was drawn by our guest speaker, Tanya Marie Silveira. Congratulations to the 2018 winners and “Thank You” to those members who continue to support Cicada by purchasing our annual raffle tickets as well as those who generously give donations.

Jane O’Neill from Wyoming - First Prize $500  
J MacDonald from Riverstone - Second Prize $200  
Mal Thatcher of Little Bay - Third Prize $100

From accumulated funds and income from donations and raffles, as well as funding our regular newsletters and flyers CICADA was able to contribute greater than $14,000 to the South Coast Clinic.

Cicada would also like to thank Polly Templeton who provides the captions for our events.

Morning Tea, 7th February

CICADA members were able to congratulate Sue Walters OAM at the first morning tea of the year, held on the 7th February. Sue has worked tirelessly as an Advocate for the hearing impaired since losing her hearing through meningococcal meningitis at the age of 22, demonstrating outstanding dedication and hardwork for the hearing impaired community. An award well deserved. Well done Sue.

Morning Teas
Held on the first Thursday of the month at Gladesville  
4th April; 2nd May; 6th June; 4th July; 1st August; 5th September; 3rd October.

BBQs and Guest Speaker/s
Sundays at Gladesville from 11 am to 3pm  
19th May; 18th August; 10th Nov AGM

Next BBQ Day 19th May
we have Rebecca Claridge, Speech Pathologist from MEDEL, speaking about auditory training, a very important topic for all recipients. Please come along and see what you can learn.

Tours of Cochlear During March
Have you ever been interested in how the Cochlear Implant devices are made?  
This is your chance. You can have a tour at Sydney Cochlear Headquarters on Friday’s 10.00 am to 2pm, during the month of March in celebration of World Hearing Awareness Month.

If you are interested, please email alatin@cochlear.com for further details.