For anybody with hearing loss, articulating the isolation it causes is almost impossible. For a child, it’s even harder. But a new virtual reality (VR) experience, designed to immerse users in a playground and classroom as a child with hearing loss, is helping to foster empathy in parents, teachers and other students. “They didn’t think I could hear so little,” eight-year-old Tyler Potaka said of his peers. Tyler has bilateral mild to moderate hearing loss, meaning he has hearing loss in both ears.

For his mother Philippa, the experience wasn’t quite so matter-of-fact. “It was very emotional to put your mind and your head and your body and transplant into your own child and to experience what they see and hear, or don’t hear. You really are able to have more empathy, you’re able to sympathise with not being able to hear.”

The VR experience was filmed at a Sydney school with students from Tyler’s class

The VR project was launched by Sydney charity The Shepherd Centre and filmed at a Newtown primary school. “We decided we should do it from the perspective of a child ... in the classroom and in the playground and do a comparison as to what it would be like with [hearing aids] and without.” Nick Hunter, the creative director from innovation company Paper Moose which led the design, said the VR team worked with audiology specialists to accurately recreate how hearing loss sounds.

"You start in the playground and the audio is quite muffled,” he said. "I was really surprised when we were talking to the specialists and we did our first pass at what we thought would be moderate hearing loss, and the expert said, ‘No, you need to go further — it’s much more degraded than that.” After experiencing the muffled audio in the playground, the user is moved to the classroom where the teacher asks you a question but you’re unable to understand. “When the whole experience was finished, and we sat down and watched it in its entirety, I found it surprisingly emotional at how isolated and vulnerable I felt,” Mr Hunter said.

"It’s wonderful to help new parents to see the impact of hearing loss and why it’s so important to help them with amplification and early intervention as soon as possible," Dr Fulcher said. And the benefit came from empathy, which would encourage parents and carers to intervene earlier, she said. “A lot of the families say they don’t want their children to wear devices because it makes them look different and the kids will bully them. “Often our reply is, ‘Well, if they don’t have hearing aids, that’s setting them up for being bullied because they will sound different, they will act different, they won’t be a part of the groups because it will be too difficult, their speech and language will be delayed; so it’s setting them up for all types of social and long-term poor outcomes’.”
Living with hearing loss is not always easy. I’m sure many have had the experience of feeling left out at times. I sometimes have to remind people that they need to speak a little more clearly or a bit slower or keep still so I can read their face better... or to get the light on their face rather than have the light shining in my eyes. I really love my cochlear implants. They give me so much information though I still have to concentrate hard to understand what people are saying.

I think most recipients understand what that’s like, and sometimes your confidence needs a bit of a boost to help you feel that you’re okay. CICADA plays an important role here providing information and reassurance to those with cochlear implants, trying to help them on that journey and give them some support where we can.

At our August gathering, we welcomed Bec Stewart from Hear For You. This group is doing a great job working with young deaf people. They are so energetic and pro-active in their approach to mentoring. They have a comprehensive program to help young people build their skills and confidence, while having lots of fun at the same time. Hear For You is creating new leaders in the community, helping people expand their social networks and find their inner strength to get through those difficult times we all experience. See Bec’s Story and report on the HFY Short Film Festival in this issue.

We all need to create awareness by telling people about our hearing loss and our cochlear implants. Don't hide it; INFORM others to help them understand how it works. Staff who care for implant recipients in hospital, especially in emergency situations and for those in aged care, need to be aware that clients cannot hear without their sound processors or hearing aids switched on. There is currently a lot of discussion on how to efficiently manage this situation and provide more training in sensory loss. Deafness Forum of Australia have been leading the way in their discussions with Minister for Aged Care Ken Wyatt AM and have achieved success in their campaign to address hearing loss training for staff in aged care facilities. The Australian Aged Care Quality Agency recently released its ‘Guidance and Resources for Providers’ to support the new Aged Care Quality Standards which will come fully into effect in July 2019. Deafness Forum have developed training programs for carers which can be viewed on their website https://www.deafnessforum.org.au/resources/training-resources-in-hearing-assistance-in-aged-care-services-and-hospitals/

Many thanks to implant recipient Alan Edwards who has also researched and written about this topic for this issue of CICADA BUZZ. See his article in this issue.

CICADA, the name of our organization which stands for the Cochlear Implant Club and Advisory Association, was formed in 1984. The first meeting was held at the Adult Deaf Society, Stanmore on 1st December of that year. Our current president, Sue Walters, the first person in NSW to receive the 22 electrode implant, was in attendance.

It was Professor Gibson’s idea to call the group CICADA, which originally stood for The Cochlear Implant Club and Deafness Association. Our logo was designed by Paul Hanke, the husband of Shirley, one of the early implantees in 1985. Shirley served as CICADA’s treasurer for many years. Alan Jones a current committee member also received his first implant in 1985.

But what do you know about the Cicada insect itself? They fill our gardens with loud sounds over the summer that can often be quite deafening. Empty skins litter our gardens and young boys like to collect and swap live specimens. The Black Prince is a prized find. Read on to find out more.

Cicadas are active underground, tunneling and feeding, and not sleeping or hibernating as commonly thought. After
The cicada’s claim to fame is its singing. The high-pitched song is actually a mating call belted out by males. Each species has its own distinctive song that only attracts females of its own kind. Cicadas are the only insects capable of producing such a unique and loud sound.

Cicadas make a variety of sounds, including very loud buzzing sounds. The males have tymbal organs that include rib-like bands on a membrane that can be vibrated very rapidly by a special muscle. The sound is intensified by the cicada’s mostly hollow abdomen. The sounds include courtship calls and squawking sounds when the cicada is handled or disturbed. Cicada males make sounds to attract nearby females, who respond by snapping their wings. The male hears this and responds by moving closer.

There are over 190 varieties (including species & subspecies) of cicadas in North America, and over 3,390 varieties of cicadas around the world. This number grows each year as researchers discover and document new species. Cicadas exist on every continent but Antarctica.
Safe Disposal of Batteries

We use batteries to run everything from torches, to cars and hearing devices. Getting rid of used batteries can cause a problem. Some contain hazardous materials, which can cause environmental harm if not discarded properly. Each year, over 300 million household batteries are thrown away with ordinary waste, with batteries being one of the most dangerous common waste discarded by Australian households.

The supermarket ALDI accepts AA, AAA, C, D and 9V sized batteries of any brand.

Recycling or correct disposal of household batteries is the best option.

Other batteries, including the button batteries used in hearing aids and Cochlear Implant processors can be disposed of at “Clean Out” council events. These are held in various locations on specified dates, usually 9 am to 3.30pm. This is a free service. Find out more information at RecyclingNearYou.com.au, launched by Plant Ark November 2006 or contact your local council website directly to find out the date of the next Clean Out in your area.

Help save the planet by safe disposal of your batteries. Every little thing helps.

AGED CARE
What happens when I can’t …

This article on the protocols for Aged Care was researched and written by Alan Edwards, a bilateral recipient and volunteer at SCIC

If you use hearing technology such as hearing aids or cochlear processors (or have one of each) you will know that caring and using this expensive equipment requires a bit of training. It’s simple and mundane things really like: how to tell the left processor/aid from the right; how to store them overnight; how and when to change a battery, microphone protector or no-wax guard etc. Although it can be a bit overwhelming at first, especially when you’ve just been ‘switched on’ it’s pretty straight forward once you get the hang of it - until that is, you have to rely on others to help you do these things.

Family and friends can get guidance from audiologists or hearing technology providers but things become more complicated if you’re in an aged care facility (ACF). Many ACFs work hard to support their residents and do a great job but CICADA is occasionally contacted by family and friends of an ACF resident asking for guidance on what to do when an ACF simply doesn’t supply adequate hearing technology support.

Why is this a problem?
• Residents in ACFs often need assistance caring for and using this equipment;
• Aids and processors are expensive. If not properly cared for they’re easily lost or damaged;
• ACF staff require training on how to support residents that use hearing technology; and
• This equipment is meant to be used. When used properly aids and processors don’t just improve understanding, they reduce the risk of depression, discomfort, anxiety and stress.

You don’t choose hearing loss, it chooses you and correctly fitted and used hearing technology is important in improving the health of anyone who is deaf or hearing impaired. We - hearing technology users let ourselves down if we fail to care for and use hearing technology properly. ACFs let their residents down if they fail to ensure hearing technology is properly cared for and used. Family and friends let ACF residents down if they don’t raise concerns when they see this responsibility is not being met. Bottom line is - each of us share this problem and want a solution.

So, what can you do if you think a family member or friend in an ACF is not getting the support they need?

1. Remember ACF are required to provide this care and there is a system ...
Not only do ACFs generally want to provide this care but government approved ACF providers are:

• required to provide assistance to residents if they have trouble caring for and using hearing technology;
• required to ensure staff and management are appropriately trained in the use and care of hearing technology;
• required to keep records that “enable proper assessments” of whether they are actually providing this assistance; and
• may be fined up to $6,300 if they do not keep records.
2. **Try to understand the cause of the issue**
Start out by identifying what the issue is. An example might be that you find the resident’s processor batteries are not being charged. One reason for this may be a high staff turnover and staff have not been trained yet. Something that could easily be fixed with a bit of training. Alternatively, the issue may be caused by a particular staff member who continually forgets to charge the batteries.

Generally issues will fall into one or more of the following categories:
- Loss or damage to aids or processors;
- Not changing batteries, microphone filters, wax guards;
- Not charging equipment;
- Not storing equipment; or
- Not fitting equipment

3. **Ask the ACF to explain how they are going to solve the problem**
Next, talk to the right people. Most ACFs have designated contact people who you can raise care issues with. Explain your concerns and ask the ACF to explain what they are going to do to ensure the situation improves.

Make sure the ACF knows who they can contact for technical assistance. Identify useful sources of assistance/information - audiologists and hearing technology providers for example.

4. **Ask the ACF to explain how they are going to assess that the problem is solved**
A good question to ask is “How will you know the problem is solved?” Most ACFs will be able to outline the systems they have to check that residents are properly cared for. This usually includes records being kept and checks that those records are accurate. The system will vary depending on the size of the facility and how the facility is managed but every system should identify what records need to be kept to show that appropriate hearing technology support is being provided to the ACF resident.

5. **Keep records of concerns**
Finally keep a simple diary of what you do. Focus on what is important and keep it very simple. Remember, you only need to keep a record of whether something that should be done was actually done. For example, whether batteries were being charged or a processor was being worn correctly. This will form the basis of feedback.

6. **Provide feedback to the ACF**
The issue may not be resolved overnight but you should notice an improvement in service once you’ve raised your concerns. If there are still issues raise them again with the ACF. They may need time to solve the problem – the ACF might try to address the issue but end up making changes that don’t solve the problem. For example the facility may train staff but the information they use may need to be updated so further training may be needed.

7. **If all else fails ....**
By this stage the ACF should have addressed your concerns. Yet sometimes issues just aren’t resolved or the standard of care is so poor that concerns need to be raised with the ‘Aged Care Complaints Commissioner’. The ‘Aged Care Complaints Commissioner provides a free service for anyone to raise their concerns about the quality of care or services being delivered to people receiving aged care services subsidised by the Australian Government.”

This is when the notes you have kept will come in handy. You can use them to show the Commissioner what has or has not been done to address the issue. Those notes will form the basis of a valid complaint. Details of the Commission’s complaint process are available at www.agedcarecomplaints.gov.au/internet/accc/publishing.nsf/Content/the-complaints-process


Details of the activities of the Commissioner are available at: https://www.agedcarecomplaints.gov.au/internet/accc/publishing.nsf/content/home

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**REPORT ON AUGUST BBQ DAY**

Many thanks to **Rebecca Stewart** who presented the **HEAR FOR YOU SHORT FILM FESTIVAL**, which was enjoyed by all at our August BBQ day.

Bec screened some of the latest short films produced by hearing impaired young people: called ‘What am I missing’ ‘Don’t Ruin Sisters Life’ ‘Circle of Love’ ‘War and Love’ ‘Love @ Chili’, ‘The Janitors Closet’ ‘Teddy Bear Love Story’ ‘Lego Story’, The Bus Stop’. Then, seeing as the kids were having so much fun, their Leaders made a movie too, called ‘How to make a movie - not’.

The films can be viewed on the Hear For You website, for those who missed out.
Here is Bec’s story.

I grew up with a hearing-impaired father and brother, along with many other deaf and hearing-impaired family members. At three years old I was diagnosed with a bilateral mild hearing loss and began wearing hearing aids at five. My hearing loss was shown to be progressive and I now have a profound loss in one ear and a severe loss in the other. Recently I received my first cochlear implant late 2017 and I continue to wear a hearing aid in my other ear.

Following mentoring through Hear For You since 2013 I recently became the Western Sydney Coordinator with the task of extending the Hear For You mentoring programs out to those living in the West. I became a mentor in 2013 hoping to pass on the baton that had been handed to me by the role models I had in my family; I realised how privileged I was and wanted to see more young people flourish. I soon realised that I would gain so much more from Hear For You than I would ever give.

In 2017 we began some new programs called Rock My World, giving deaf and hearing-impaired teens a chance to try some new activities, including filmmaking. We worked with a group of 6 teenagers to make 2 films in 2 days and it was tough but they did brilliantly, some talented teens even went home and made more films at home. We showed their films on the big screen at Golden Age Cinema and it was all round an amazing experience. Following the Film Festivals success last year, we decided to launch it nationally this year and received entries from Hear For You participants in Queensland as well as Sydney. It has been amazing to see how talented these teenagers are and it is clear how much potential each one of them had.

**CICADA Australia Inc.**

Dates have been set for Cicada functions for 2019. Put these in your diaries. All Cicada functions are held at SCIC, Punt Road Gladesville. Morning Teas from 10.30 to 12 midday and BBQ’s 11am to 3pm. Flyers with details of the guest speaker at the BBQ’s are sent out prior to the day.

### Function Dates for 2019

#### MORNING TEAS
These are held on the first Thursday of the month from February to October

- 7th February
- 7th March
- 4th April
- 2nd May
- 6th June
- 4th July
- 1st August
- 5th September
- 3rd Oct

#### BBQ’s
The date for our first BBQ has not been finalized, but other dates are:-

- 19th May
- 18th August
- 10th Nov – AGM

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**Please Note**, the **CICADA AGM for 2018** will be held on **Sunday 11th November**. See details of the day on the enclosed flyer.

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**28th Annual General Meeting of Cicada Australia Inc.**

11th November 2018

**Agenda**

* Welcome to members and guests
* Apologies
* Acceptance of the AGM minutes from the 12th November 2017
* Matter
* Arising
* President’s Report - Sue Walters
* Treasurers Report - Chris Boyce
* Office Bearers and Committee Members to vacate their positions
* Ratification of Office Bearers and Committee members for 2016/17
  (if nominations received are not in excess of vacancies available, no election is required)
* Elected President takes the Chair
* Vote of thanks to committee * The Year Ahead * Close of meeting
Support Groups

See details for each of the groups below. Also see the CICADA website for up to date details of these events

www.cicada.org.au

Goulburn Support Group

There has been some interest in starting up a support group for recipients in the Goulburn Region.

A "local" support group has lots of benefits for members. It doesn’t need to be too much work, just a group of interested and dedicated people who are willing to work together to help others, can share their stories and help each other out when needed. It is a valuable resource for those who have lost their hearing and are seeking information, also for reassuring recipients who have been recently switched on and want to practice their social skills.

A local community group such as Lions, Rotary, Probus or Quota Club might be willing to team up with recipients to help them start up a group and provide a sausage sizzle or afternoon tea. Local clubs, church halls, community centres, scout halls or other meeting places can be utilised as a venue.

If you have a CI, it is good to share this information with your community to increase awareness of hearing loss generally and improve the quality of information that is circulated.

Common MIS-information is that CIs are “only for children”, or “only for congenitally deaf” or “only for profoundly deaf”, though the criteria for eligibility has changed over time and even people with single-sided deafness can now be considered for a cochlear implant.

If you are interested in this idea, please contact:
Judy Cassell – jcassell6@bigpond.com
or snail mail PO Box 5028
South Turramurra, NSW 2074

Illawarra

David reports on the September BBQ held at Windang.

Wow – what a day it was yesterday at the Illawarra CICADA Picnic at the Windang/Lake Illawarra site. While the warm sun was out, the super strong winds did certainly challenge many of us with our hearing, even I was struggling big time!

Despite this challenge, it was just super awesome to see everyone in great spirits and enjoying the company of one another. I still believe this is the reason why the group continues to go strong at each event.

A special shout out and thanks to Bill who was up bright early and secured us the better shelters that was near the Picnic BBQ’s that were on site. Because of Bill’s efforts, we were about to have a last minute impromptu cooked sausage sandwiches for lunch, which I’m sure many of us enjoyed! Thank you Bill!

Also, David (Felix’s dad!) and Ray did a great job cooking the snags for us.

And thank you to everyone else who turned up for the day and also for bringing a great variety and selection of foods to eat.

Dates for the Balance of the Year

Sunday 9th December
Windang Picnic Parks Xmas Party

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

Newcastle and Hunter Valley

A very successful meeting was held last Wednesday 10th October. Sharon Lown, the new Regional Manager for Newcastle SCIC joined us for the morning tea. Sharon introduced herself to us all and took the opportunity to chat with those attending. It was good to put a name to a face.

We also had the pleasure of meeting Anna Molski from Cochlear. Anna had a chance to interact with our group who were able to let her know how they appreciated their implants.

It was good to welcome a number of newcomers; some having just received their implants with others considering their options. Family members also came along and I’m sure gained valuable information to help them understand the support needed by the recipient to transition to a world of sound.

Come along to our December Christmas party on 12th December. All are welcome.

For information about morning teas at SCIC Newcastle – held on the 2nd Wednesday of EVEN months, contact:
Moira Havard - moirak@bigpond.com
Alison Gron - 4926 8100

Northern Rivers

What a year we have had, people from all walks of life sharing their amazing, and sometimes, bumpy, hearing journeys with one another. It’s a pleasure and privilege to be part of a group that is so willing to empower others by sharing their heart felt experiences.

This journey is different for everyone, for some, meaningful progress is noted within a few weeks, for others, it may take months or years. Thank you to everyone for creating a safe and non judgemental environment, where participants can freely express their joys, fears and frustrations. As well, thank you to Seacoast Church for freely providing us with such great facilities.

Our shared end of year dinner will be held Thursday 6 December 6:30 pm at Seacoast Church Ballina. Invite your family and bring something yummy to share. Please RSVP: sheliyavan@yahoo.com or phone or text: 04225242

Sheliya Van Buggenum - sheliyavan@yahoo.com or Phone or Text 0422 524 284 OR Phone Lismore SCIC Office on 1300 658 981
Taree-Port Macquarie
For information and details of the groups activities please contact: -
Robyn Herps robynherps@westnet.com.au
Phone SMS 0428 688 612

Western Sydney
Morning teas are held on the First Tuesday
of the month at the Royal Institute
for the Deaf and Blind Centre at 5-7
Floribunda Avenue, Glenmore Park,
from 10.30 to 12 noon. All are Welcome.

For those travelling by public transport,
there is a bus – 797 – from Penrith station
at 9.56 that stops out the front of RIDBC

For further details contact
Sean and Margaret Sewell on Mobile
+614 2521 5654 or 041 5205 877
Judy Tutty – Co-coordinator 0437 049 452

‘I loved the deafened world
place of magnificence and
revelation. But I
was always just a
tourist’
Sept 2018 Toronto Star

In this excerpt from Sound: A Memoir of
Hearing Lost and Found, Greystone Books
2018, English author Bella Bathurst writes
about how silence and sound contribute to
our lives. And she tells the personal story of
losing her hearing for 12 years — and then regaining it.

Sound had come back into me with the
force of revelation and I had no idea what
to do with myself. I could hear! I could
hear!!!! I’d been hearing for 28 years and
deaf for 12, and since I’d gone back to being
hearing again, everything was bigger than
I had the capacity to express. I wanted
everything. I wanted to try everything,
listen to everything. I wanted to go up to
strangers in the street and ask them if they
had any idea of the miracles taking place
inside their heads. I wanted to tell them
that this hearing thing — this basic feature,
fitted totally as standard in every working
model — turned out, upon examination, to
be a piece of kit which made the works of
Shakespeare seem slack by comparison.

I sat in cafés, blissed by the opportunity
to eavesdrop on people bitching about
their colleagues. I struck up conversations
with strangers on trains or found excuses
to offer directions to tourists. I rang
up friends in Orkney or Greenock just
because I wanted to hear the way they
said “modern” or “cosmetic” and savoured
the tastes of each professional dialect —
the wipe-clean tones of nursing staff or
get-in-quick diction of cold-callers.

But just how well does the therapy work?
To find out, Rhee’s group looked at data
from 19 studies that compared outcomes
for people with sensorineural hearing
loss. Patients either received drug therapy
alone or drug therapy plus hyperbaric
oxygen. A total of more than 2,400
patients, averaging 45 years of age, were
included. The team found that people who
had the combo therapy were 61 percent
more likely to achieve complete hearing
recovery compared to people who only
got medicines. The average amount of
hearing recovery was also higher, overall,
for people who got both therapies rather
than drugs alone. Also, hyperbaric oxygen
appeared most helpful for those patients
who had experienced the most profound
hearing loss.

Therefore, adding hyperbaric oxygen
therapy to steroids or other drug treatment
seems to be a “reasonable option” for
people with this form of sudden hearing
loss, Rhee’s team said. Kohan did have
a few caveats, however. First, he said
the analysis couldn’t control for certain
variables -- the dosage and timing of drug
treatment, for example, or the presence
(or not) of vertigo or tinnitus (ringing
in the ears), which often accompanies
sudden hearing loss.

He believes that “far more studies,
with much more stringent criteria and
controlled variables are required to make
more definitive conclusions.” Finally,
there’s the cost of hyperbaric oxygen
therapy. The study found that benefits
usually appeared after at least 20 hours
of therapy, and Kohan noted that hyperbaric
oxygen typically costs $300 per hour in
the United States.

Study supports
oxygen therapy for
sudden hearing loss
Sept 2018 UPI.com

Viruses and blood flow issues can, in rare
cases, trigger sudden and profound hearing
loss. Now, South Korean research supports
the use of hyperbaric oxygen treatments
to restore hearing in these patients. A
review of the collected evidence suggests
that -- added to standard drug therapy --
hyperbaric oxygen treatment “is the most
beneficial treatment option” for what
doctors call “sudden sensorineural hearing
loss,” according to a team led by Dr. Tae-
Min Rhee. He’s a specialist in hyperbaric
medicine at the National Maritime
Medical Center in Seoul.

One expert in the United States explained
that this type of sudden hearing loss is
rare but very troubling to patients.
"Sensorineural hearing loss occurs in about
1 out of 10,000 people,” said Dr. Darius
Kohan, and is thought to be triggered by
a viral infection or circulatory problems
within the ear. Kohan directs otology at
Lenox Hill Hospital in New York City. He
said that 1 in every 3 people will get their
hearing back without any treatment. For
the other two-thirds of patients, drugs
-- most often steroids -- are used, as well
as hyperbaric oxygen. In this treatment,
patients are placed in a device that boosts
oxygen levels in the inner ear.

Therefore, adding hyperbaric oxygen
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