John, or Johnny as he was known to most people, was born in the suburb of Leichardt in 1947, moving with his family to Narrabeen in 1958, spending most of his years on the Northern Beaches.

Johnny’s involvement with CICADA began in 1998, when his wife Chris, the current treasurer of Cicada, had her first implant. A wonderful asset to Cicada, he was a great “meet and greet” person at Cicada functions, seeking out new visitors, making them feel at home and introducing them to other implantees.

He was part of a dedicated group that set up for morning teas and BBQ days, as well as dismantling at the end of the event. He made and for a number of years ran a Chocolate Wheel at our BBQs, raising money for Cicada. He spent much time behind the scenes organizing the annual raffle, printing and collating the booklets. He had great skills at sourcing items on the Internet – at a very good price – when Cicada was setting up the Club Room. He was always involved in the regular mailouts: putting on the RTS stamp, postal stamp and address labels, before a flyer or the Buzz was inserted into the envelope. In fact, prior to his death he has already prepared the envelopes for the mailout for this edition of the Buzz.

Johnny had a great sense of humour. In May 2009, a number of the Cicada committee and partners had a weekend away at Orange. A local Support Group was being set up and the visit was to provide support. Johnny hired a local community bus and off we set. Prior to departure he issued a lengthy set of Coach Rules, with fines for those who offended. A great weekend was had by all, with little revenue being collected.

John’s many skills included the position of Cicada’s head Chef, his reputation in producing the best BBQ Sausages and Onion was widely acclaimed and eagerly sought by members and friends attending Cicada social days.

Johnny will be greatly missed by Cicada for his happy, welcoming, outgoing manner and the generous contribution of time, planning and energy that he has contributed over the years.
**State CICADA Associations**

**New South Wales**  
CICADA AUSTRALIA INC.  
Secretary: Judy Cassell  
PO Box 5028  
South Turramurra NSW 2074  
Email: cassell6@bigpond.com

**Queensland**  
CICADA QUEENSLAND  
Secretary: Shirley Edwards  
Email: info@cicadaqld.com.au

Shirley Edwards: shirley@hotchipz.com  
Penny Phillips: pennyphillips1@bigpond.com

**South Australia**  
CICADA SOUTH AUSTRALIA  
Email: contact@sacic.com.au  
Ph: 08 8379 4500 (Nina)

**Western Australia**  
CICADA CLUB W.A. INC.  
Chairperson: Edna Chapman  
Email: eknit57@hotmail.com  
Ph: 9401 8164

Treasurer: Ted Ivey  
Email: ted2laura@gmail.com  
Ph: (08) 9371 5650

Secretary: Jane Humby  
Email: legend.26@bigpond.com  
Phone: 9733 2447

**Northern Territory**  
CICADA DARWIN  
Coordinator Chris Blackham-Davison  
Email: Deafncrazy@gmail.com  
SMS: 0427 897 170

**Canberra**  
For information contact  
Glenn Vermeulen: glen.vermeulen@gmail.com  
SMS: 0427 897 170

**Hook Up Online And Share Your News**  
Please visit us at www.cicada.org.au  
Or our Facebook page Cicada Australia Inc.

Darwin friends now have their own  
Facebook page Cicada Northern Territory

Donations over $2 to CICADA are tax-deductible.

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If you would prefer to receive this newsletter by email, please send your details to suewalters@cicada.org.au

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**Presidents Report**

It is with great sadness that we heard of the passing of John Boyce, CICADA’s Right Hand Man and husband of Chrissy Boyce our long time treasurer. Judy has written a tribute to him in this newsletter and I can certainly say that he will be missed by many. Always welcoming and helping people to feel included at our events, it is a great loss to us. My heart goes out to Chrissy and family who, behind the scenes, have helped to make CICADA AUSTRALIA what it is today.

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**Inaugural World Hearing Forum, Geneva**

I was invited to Geneva in Switzerland just before Christmas to participate in a meeting of cochlear implant advocates from all over the world.

The theme for World Hearing Day 2020 is “Hearing For Life…Don’t let hearing loss limit you”. With this in mind, (I am reminded!) that so often, we should focus on wanting what we have, as opposed to having everything what we want!

I know that living with hearing loss can be difficult, but one of the best things we can do is speak out and tell people our concerns or difficulties to help them understand the issue. Sometimes we miss things, but hearing loss doesn’t have to limit you from participating in life. Use what you have to best advantage. Sometimes it’s a change of attitude that we need to help us see the best in things.

I saw a slogan on a T shirt recently. It was from the Cirque du Soleil, the Montreal circus that tours the world. The slogan said, “we rise by lifting each other”. This said so much to me and it made me think of how many people have supported me and continue to support me, to help me do my best such as family and friends and the CICADA Committee, for instance. We come together to hold these events. We enjoy helping and reassuring people that the Cochlear implant can make a difference.

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The World Health Organisation has recognized that hearing loss is a global public health concern and seeks to promote awareness and action on hearing loss through global collaboration and advocacy. The Inaugural World Hearing Forum meeting was held at their headquarters 4-5 December 2019, with a particular emphasis on cochlear implants as an effective treatment for severe to profound loss of hearing. The Consumer and Professional Advocacy meeting on 6th December, in which I took part, included audiologists and ENT doctors, but mostly recipients from many countries, who work in advocacy to ensure that the patients voice was heard alongside the professionals. Implant recipients are the best advocates for the CI and it is hoped that together with our respective organisations (e.g. CICADA) we can raise awareness of the benefits of CI’s and also the best clinical practice for follow-up support of patients with CI’s so they get the best results with their implants.

The WHO are expected to release a paper in May 2020 on the findings of this meeting and proposals to work together to achieve better hearing health globally. For me, it was a rich opportunity to get acquainted with recipients from other countries, to hear their stories. It was interesting to hear about their respective advocacy organisations and learn about the way their CI programs are structured.

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Qld Christmas Party  
I received an invitation to speak at the Queensland CICADA Christmas Party lunch, held at Alexandra Headlands Golf Club, Buderim, last year on 30th November.

It was so encouraging to see a good crowd of supporters, some travelling from the
Gold Coast and Brisbane for the day. Penny Phillips did a wonderful job organizing everything. She had loads of prizes for the raffle, all beautifully wrapped, a big job in itself. I know she had help!! They had a fabulous guest speaker in Barry Bull OAM, a veteran musician and entertainer who started up the iconic Toombul Music store in Brisbane. Barry spoke about his current volunteer work, singing and playing guitar with deaf children at the Hear and Say Centre and how rewarding this is for him. Barry sang some lovely songs for us accompanied by his guitar.

Dr Kristy Fraser-Kirk, Director of the Sunshine Coast University Hospital, also presented on her medical background and current work as a cochlear implant surgeon. I also met Louisa Handyside and her husband, a young woman, recently implanted who has been inspired to start up a Toowoomba CI support group. Best wishes to Louisa, whose first event was on World Hearing Day at the Toowoomba Library.

Congratulations Queensland CICADA on maintaining strong support networks for those with CI's.

Roma Wood OAM
1926 – 2020

Born in Maitland NSW in 1926 Roma grew up with hearing loss, which accelerated rapidly during her teen years. She was 18 years of age before she received her first hearing aid and she wore a body hearing aid for about 30 years.

The growing-up years can be traumatic – experiencing childhood fallacies as the years progress – the teenage years when one is becoming a woman – I think that was the most difficult part of my life.

I can still remember what it was like to grow up having a severe hearing loss and experiencing the unkindness and cruelty of other children. But it was the "Teenage years that made me feel that I was different, that my life wasn't going like other girls.

My independence started when I began working and proved to my family that I could be responsible for my own decisions.

The above quotation is from a paper presented by Roma at a Rehabilitation Conference at Macquarie University in 1993.

In the 1980’s she transitioned from Dressmaker to full time student and educationalist which kept her busy studying, delivering Public addresses, attending conferences or travelling with family. In the following years, Roma received many awards and she was recognized both nationally and internationally as an expert in her field.

In great demand as a public speaker Roma was the winner of a Churchill Fellowship in 1982 that took her on a 10 week study tour to rehabilitation centres for the deaf in Europe and the USA. In the late 1980’s she was named Quota International’s Woman of the Year in the South Pacific Area. In 1990 she was honored with an OAM for her contribution to working with the deaf.

Roma went on to become the coordinator/teacher training (NSW) with Better Hearing for over 45 years. She was a great advocate for lip reading and was the author/co-author of various Aural Rehabilitation and Lipreading Manuals and Speechreading articles. Over the years, Roma held many leadership positions with Better Hearing Sydney as well as the national body, Better Hearing Australia Inc.

In 1994 Roma received her first Cochlear Implant followed by her second in 2009. Some of her reflections following her first implant are as follows.

"Localized direction of sound is something that I am having success with. I practice listening for trains, and check when an aeroplane flies over. I check anything specific. The best thing is that I am more confident that what I see, is what I hear.

The difference in meetings or socially is amazing. Before I had to wait till I saw people’s lips stop moving to know they had finished speaking. Now, I am conscious of the fade out of their voice and can respond more quickly.

All the sounds that I now hear – car tyres whizzing past – rain on the roof – the click of the traffic indicator – so many noises but the best is the sound of people speaking.”

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Roma at a Cicada function in 2016

A great supporter of CICADA, Roma had an outgoing personality with a very positive approach to life. She was a staunch advocate for the hearing impaired and a great inspiration to others with hearing loss.

We extend our sincere sympathy to the family and friends of Johnny and Roma.

Nurse came in and said Doc, there’s a man in the waiting room who thinks he’s invisible, what should I tell him? The doctor said Tell him I can’t see him today.
A Return to Co-ordinator of the Illawarra Group

Sue Young

It's great to be back! For those who don't know me, I actually started the Illawarra CICADA Support group in 2008 as part of my studies at the University of Wollongong in Population Health. At the time, the group commenced in conjunction with SCIC, Gladesville supported by my original and wonderful audiologist Monica Bray. As the group was so well supportive and sustainable, it merged under the banner of CICADA, servicing recipients in the Illawarra plus some recipients from the far south coast.

At the time there were no support groups suitable for us overwhelmed recipients (like me!), family or friends. There were no outreach centres. For me personally all my mappings and switch ons were conducted after a (sometimes long) trip to SCIC in Gladesville that at times took 2-3 hours travel.

Fast forward from my first CI in Sept 2004 (right ear) and my 2nd CI in June 2006, a whole new world has opened for me. I like to describe my journey as from a Black and White World, to a World now full of Colour and Sound. What a ride it has been!

My hearing journey commenced by a chance meeting with Prof Clark (the inventor of the original CI) at Kiama in 2003. Since 2004 and my first implant I commenced University and completed a double degree, plus some additional Master subjects, learnt to dance, presented a TEDX talk, gained a professional position and signed up with Cochlear Aust as a voluntary research recipient (since 2006). I still continue to visit Cochlear HQ when required, often on a fortnightly basis. I continue to present talks for community group and to various employers on hearing loss, prevention and the Cochlear Implant Program.

I am now a Case Manager, Support Coordinator and Service Facilitator for Aged Care and NDIS with my own NDIS package associated with my hearing loss. I plan to be allocated a Lions Hearing Dog in the future and finally retire in 2-3 years. But I also plan to continue my community work long into the future and hopefully link this to travelling around our beautiful country. As a foodie I am also collecting data on eating out locally with a hearing friendly. Oh and yes, I get to taste some very yummy food. I am yet to get this published but optimistic it will occur one day... meanwhile I continue to eat, drink, talk and love. I am also a member of Quota International and the nominated Hearing and Support Officer. Quota helps children with hearing loss plus disadvantaged women and children. Quota also is closely associated with The Shepherd Centre for fund raising and support.

But sadly post CI my marriage developed a used by date and hubby and I parted as friends in 2010. New love however has blossomed with a friend whom I have known for over 9 years. The big news is, I will be getting married in April!! Let those bells ring!

As Illawarra CICADA has been running smoothly since 2008, I would like to make a very special thanks and congratulation to Bob and David who have taken the reins in continuing to facilitate your wonderful support group. Bob especially for the wonderful work he continued when I had to step back from the group due to personal reasons. Sue Walters has continued to support the group as well as Jo and Felix. There are many more I would love to thank- I may not know you, but I know you have assisted to keep this group going. From producing lovely baked goodies to share, to cooking the BBQ, connecting with others whilst lending a supportive ear when needed all which makes this group unique. Also to our Sydney and Far South (or north) visitors who come to see what all the fuss is about.

Sue Young

Sue with Alex Gibson at Taree 2017
ICI Day is 25th February each year, so CICADA celebrated this as our first BBQ day for the year on Sunday 23rd February at SCIC Gladesville and 130 visitors came along to enjoy the day. Representatives from Cochlear, MEDEL, Hearing Connections, SCIC/RIDBC and the Bionic Ear Association all supported our day to make it a collaborative event.

Cheryl Musumeci was helping at the Welcome Desk and not many know that Cheryl was one of the original pioneers of the CI, the 4th recipient in Graeme Clarke’s Melbourne CI program in 1982. Cheryl lost her hearing from meningococcal meningitis in 1978 and her mother wrote to Graeme Clark when she read about his experimental work. Cheryl had to move to Melbourne and live there for a year, spending many days connected to a wall full of computer banks while the team tried to develop a portable sound processor.

Viktorija McDonell from Cochlear was our guest speaker and presented on her work in Uzbekistan, establishing auditory habilitation programs for children who have received Cochlear implants provided by the Uzbek government. It was such an engaging talk, with short videos showing exactly how they work together to teach the child to LISTEN, with the child’s parents, an Uzbek teacher and Uzbek/English interpreters, such a challenge.

Viktorija has a wealth of experience in this field as she is also the mother of Holly, who was the first child in NSW to receive a CI in 1987. There was no formal habilitation program then, so Viktorija had to sort of make it up as she went along, teaching her child to hear again after a CI. Once Holly started school, Viktorija started a Masters in Special Education and trained as a Teacher of the Deaf. Heartfelt thanks to Vikki for her wonderful presentation.

Thanks to Cochlear for providing live captions and live streaming and MEDEL for bringing Brett Bower the caricature artist who drew some comical portraits. CICADA provided our premium sausage sizzle, cakes and beverages and the jolly and colourful Black Joak Morris Dancers were livening up the day with their bells on.

The full transcript of Viktorija’s presentation is posted on our CICADA website and you can also watch the live video from this link: https://vimeopro.com/pascoeberry/cicada-live

The World Report on Hearing by the World Health Organisation is due to be published Sunday 17th May 2020. It will be available online for free download at https://www.who.int/activities/highlighting-priorities-for-ear-and-hearing-care

The report will deliver a cohesive narrative on hearing loss and ear and hearing care that is based on the best available evidence; outline the shift in the epidemiological distribution of hearing loss globally; highlight best practices for ear and hearing care; and provide guidance to Member States on recommended interventions. The report will work towards establishing links between addressing hearing loss and achieving many of the UN Sustainable Development Goals, notably those relating to ending poverty (Goal 1), ensuring healthy lives (Goal 3), improving chances for education (Goal 4), and promoting employment opportunities (Goal 8).

Please help us save on postage costs

CICADA Committee would like to have your email address so we can send out urgent notifications or flyers by email which is quicker and less costly for us.

If you are willing to receive your BUZZ by email rather than by post, this would also help reduce costs for us going forward.

However if you want to receive a hard copy BUZZ in the mail we are happy to still post one.

Please advise suewalters@cicada.org.au of your current email address to nominate a posted or electronic version of the BUZZ.
Our President Sue Walters opened the AGM by acknowledging the traditional custodians of country throughout Australia, to the Gadigal people of the Sydney area and in particular to Wallumedegal tribe that lived in the Ryde, Hunters Hill area. She also acknowledged those who gave their lives and those who faced combat in war – Monday being Armistice Day.

Sue thanked the CICADA Australia committee “who’ve worked hard again this year to provide our morning teas and barbecue days. I’m just so grateful for your continued support. We’ve a number of people who commit their time regularly who are not on the committee who I would like to thank for their valuable contribution. I also want to thank all the implant recipients, friends and families who come along and support the CICADA and the implant programme. We have had the presentations live-streamed this year and that was a first for CICADA. So thanks to Steve Pascoe for offering this service for us.”

There were no changes in the CICADA committee elected, with the results as follows.

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

The results of the annual raffle draw were:

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<td>Mrs K Fischer</td>
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<td>Kevin Cole</td>
<td>Beaumont Hills</td>
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CICADA is extremely appreciative of the continued support of so many CICADA members, thorough their purchase of raffle tickets or giving donations in lieu of, which help CICADA to fund their activities.

Sue introduced the guest speakers, Andrew and Bec Stewart.

Andrew and Bec Stewart
AGM Guest Speakers

November AGM guest speakers were father and daughter team, Andrew and Bec Stewart.

Andrew worked in assisted technology with Printacall as technical manager for 34 years and following the organization change of hands, he decided to set up his own business Hearing Connections.

Andrew grew up in a family of people with hearing loss. Nine people in his extended family suffered from hearing loss; wearing hearing aids, cochlear implants or a combination of both. He went on to have children who also suffered from hearing loss and even the dog went deaf! As a result family gatherings were often noisy and exhausting affairs as the hearing impaired tried to follow the conversations.

Andrew had his first cochlear implant 11 years ago and a second, four years ago. Bec started wearing hearing aids when she was five years old and had her first cochlear implant two years ago. She has a passion for advocacy and education and has used her cochlear implant journey to educate her friends and community.

Andrew and Bec both talked about the importance of empowerment, accountability and taking responsibility for one’s hearing loss as well as the use of assistive technology to help in various hearing situations.
Support Groups

Illawarra

EVENTS for 2020
TIME:
All events Sundays 10:30-2pm unless otherwise stated.

WHEN:
5th April - The Australian Motorlife Museum
14th June - Lunch at Port Kembla Collegians Leagues Club - 11:30-3pm
2nd Aug - Foreshore Park Windang.
18th Oct - Shellharbour Pools
29th Nov - Xmas Party TBC

Newcastle and Hunter Valley

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

Moira Havard reports, “Our Christmas meeting was well attended and all indulged in eating some delicious food with our cuppa.

We had our first CICADA Meeting last week and had a good attendance. I put out an expression of interest to the group to ask if anyone was interested in visiting the place where our amazing hearing devices are made and put together. A number of members have said they would love to participate so hopefully I am able to get things together for a visit in April.

The girls at SCIC Newcastle are so helpful in getting these gatherings happening, a big thank you to them.”

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

Taree-Port Macquarie

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

Northern Rivers

The Northern Rivers Support Groups continue to meet on a regular basis. The next get-together will be held on Thursday 7th May from 10am, at the Seacoast Church.

For further information contact:- Sheliya Van Buggenum - sheliyavan@yahoo.com or Phone or Text 0422524284 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

The group meets on the first Tuesday of the month.
Currently meeting at the café at Penrith RSL Club, 8 Tindale St Penrith between 10am-11.30am.

The April meeting will be for lunch from 11.30am at the Pioneer Tavern Bistro, 21 Aspen St, South Penrith on Tuesday 7th April.
ALL WELCOME

Judy Tputy - Co-coordinator
043 704 9452

CapTel steps in to keep text-captioned telephones running for Australia's deaf community

CapTel's US operation has stepped in to temporarily keep their text-captioned telephone service running for Australia’s deaf community despite the Federal Government cancelling its deal with the service provider.

The service was set to end after January 31, but CapTel is continuing captioning for Australia. The captioning is being temporarily provided from the United States. Thousands of hearing-impaired Australians feared losing the service as of February 1 after the Department of Communications declined to renew the United States service provider’s contract with the National Relay Service (NRS) in favour of another company. CapTel said the captioning service would continue to deliver captioning as an interim measure outside of the NRS. Captioned Telephone International president Rob Engelke wrote to users telling them he was optimistic the Federal Government’s decision could change, but for the “near term” captions would be delivered from US captioning centres.

“I have been genuinely moved by the outpouring of heartfelt messages from Australians who are clearly distressed and frightened about living without CapTel,” he said.

For more information contact
Sue Young - SMS 0403 508 730
Email sbv218@uowmail.edu.au
Moisture and Dirt

Ear Gear is not only the perfect solution for infants and toddlers, giving worried parents peace of mind, but it is just what the doctor ordered for active school age children, in the playground, or around the house.

Adults love Ear Gear too, they use it for dirty, dusty, or wet work environments, in the garden, while mowing the lawn, or during any sort of sporting or outdoor activity such as running, biking, hiking, fishing, or canoeing. Ear Gear is great for anyone who has an active lifestyle.

Seniors find Ear Gear gives them peace of mind as they can always locate their hearing instruments. This makes Ear Gear a ‘must have’ for any resident of a nursing home.

T: 07 3852 4622  F: 07 3852 4633

Keeping Seniors Connected

We are asking CICADA members to support a campaign aimed at greater fairness in funding. As Australians, we can be proud to be the home of the implant, and to live in a country with support for recipients. For example, today, most Australians can receive cochlear and bone conduction implantation through the public or private health system. Also, most Australians can receive regular replacement sound processors and access to technology advances. However, there is one group where funding is a challenge – people who are aged 65+ when they receive their implant and who do not have the right private health insurance. For them, there is no access to public funding, leaving this group vulnerable, and in some case reliant on charity to avoid being “off air.”

And the thing that doesn’t seem fair is that if these same individuals needed a hearing aid, they could most likely get one through the Hearing Services Program.

As many of our members know, a program, spearheaded by RIDBC (formerly SCIC) and supported by the NSW state government resulted in a 3-year program, where 400+ recipients, without private health insurance were able to receive replacements. However, this program was a “one off”, only occurred in NSW and has now ended. It also was only for NSW residents, leaving recipients from around the country without an option.

In short, we want to raise our voices to help people in other states who are falling in the “gap” of public funding. We are encouraging members to email (or snail mail!) key leaders in the hearing, aging and disability space. By raising our voices, we aim to help bring this issue to light and help close the funding gap.

Please help add your voice to this campaign
Contact Sue Walters for further information suewalters@cicada.org.au or through CICADA AUSTRALIA P.O.Box 5028 South Turramurra NSW 2074

World Hearing Day 3rd March 2020

A breakfast gathering of NSW Parliamentary Friends of Hearing Health and Deafness to celebrate World Hearing Day at the NSW Parliament House brought together MP’s and Representatives from various hearing/ deaf organisations: Cochlear, RIDBC, Australian Hearing Hub, Deaf Society, Shepherd Centre, Hear For You, Hearing Australia. The event was sponsored by Macquarie University and Deafness Forum. It was a good opportunity to network and learn about the various research initiatives that are conducted by these organisations that contribute to better outcomes for hearing AND overall health.

David Brady, Chair of Deafness Forum accompanied by AUSLAIN Interpreter Sean Sweeney, spoke about the ideas they have been working on to engage our MP’s in the issues of hearing loss to get more recognition for this public health concern. MP’s were offered hearing screening tests to check their hearing and some MP’s wore dosimeters in the House to record the levels of noise they are subjected to in parliament and at Question Time. David said that some MP’s didn’t want their hearing checked “I don’t want to know”... and the point to get across is that while prevention is important, there is quite a bit of fear and anxiety associated with hearing testing and the possible outcome. That stigma around hearing loss is hard to get around!

Professor Catherine McMahon presented the combined results of the hearing tests on MP’s and the noise levels in parliament sittings and it was surprising to find that UNSAFE levels of noise are fairly common. Felicity Wilson MP for North Shore is one of the MP’s who has shown interest in this concern and she also spoke at the event. Macquarie University and National Acoustic Laboratories had a marquee erected in Martin Place for World Hearing Day to promote general awareness and preventative measures for hearing loss. Uni students in red Tshirts were recruiting members of the public to come and have their headphones tested by “Harry Hearsmart”, a device that can report on safe volumes for listening. They were also giving away reusable silicon earplugs to protect hearing in noise.

Protecting your processor

Do you know that dogs love to chew sound processors??
Every year there are a number of processors that are chewed to bits, when processors are left in a place where a dog can reach it. They must smell so good!!

Please if you are taking off your processor for any reason, always put it in a small container, preferably with your name and phone number. Processors can easily slip out of pockets or other places and if they have no identification on them, they are LOST!!