

## Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 15 April at Hearing Auckland (Hearing Association), Remuera, Auckland.

Hosts: Maxine and Donna.

Present: Donna, Maxine, Vince, Raewyn, John Neale, Donald, Stuart, Laurie, Gloria and John.

Apologies: Caroline, Louis and Mona, Kerry, Pam, Karel, Rod and Helen, Des and Gay, Di, Bea, David Merryweather, Michael Lee, Maurice and Patricia (Whangamata), Anita and Frank and Raewyn A.

*Donna welcomed everyone and thanked Maxine and Donna for today's morning tea.*

Please remember to check the Pindrop Foundation website. There is a lot of information available from the recent forum. Lots of downloads and videos to recap the day's events. <http://www.pindrop.org.nz/>

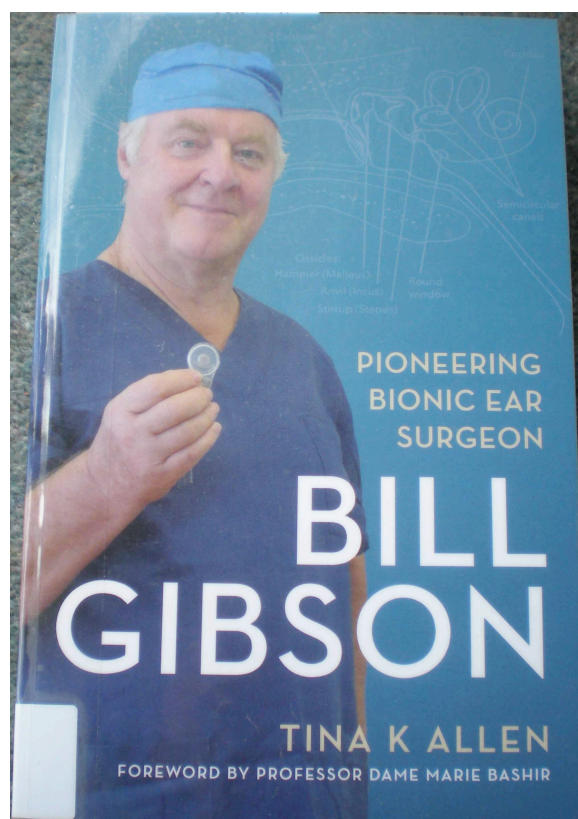
Viv Welham has made contact to say she is finally getting her CI on June 22 after having waited for a number of years.

Recently reading a book written by Evie Mahoney (What does the sea sound like?) 'Memoirs of CODA' (Child of Deaf Adults) there was a lovely poem which is below, author unknown.

Blessed are they who seem to know  
That lip reading is difficult and slow  
Blessed are they who shake my hand  
And write notes to help me understand  
Blessed are they who know that I long  
To hear voices, music and song.  
Blessed are they who seem to see  
That I am lost in a group of two or three.  
Blessed are they who take time out  
To explain to me what they are talking about.  
Blessed are they who are patient and kind.  
That makes my life worthwhile.  
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### Biography

Having recently come across the launch of Bill Gibson's biography, Donna requested that Auckland library purchase a copy (or two) which they have done so. Bill Gibson is one of the CI pioneers in Australia in conjunction



with Professor Graeme Clark (doctor) and Jim Patrick (CI engineer) and over his 30 years within the CI industry, implanted over 1000 patients. He has recently retired.

*Just as an aside, the word cochlear is Latin for snail.*

## **CICACA**

As a result of looking around the web, she came across the Australia Cochlear Implant Club and Advisory Association (CICADA). [www.cicada.org.au](http://www.cicada.org.au)

There is a wealth of knowledge on this website, including downloads of the buzz newsletters. <http://cicada.org.au/~cicada45/index.php/buzz-magazine> Having been in contact with the web designer these only go back to 2014 and previously were hard copy (i.e. magazines).

Also note to the right hand side of this website, an updated version (2016) of their Hearing Loss and Hearing Solutions guide. (Please note its 57 pages)

Stories from members = Queensland - <http://www.cicadaqld.com.au/archive.html>

Links to other websites - <http://www.cicadaqld.com.au/links-to-related-sites.html>

*A great way to spend the Easter weekend.*

## **Talkaround**

Donna had had contact from Chris Read before Christmas. He used to belong to the Hearing Association a number of years ago. Also too he had been a reporter. Maxine suggested he would be great to have as a guest speaker.

Donald had recently purchased a new N6 processor. The FM one was an extra \$6,000.

Raewyn: I recently had to make a number of business contacts including the bank and insurance companies. They did not understand what the CI was and she had to tell them. Of particular interest the insurance company did not understand that there were internal and external parts involved.

Maxine: I think to get some interest and information about cochlear implants, we need to get someone on Shortland St as a cameo appearance.

Donna: Recently some CI people have had hospitalisation and we need to make sure our needs are covered.

Stuart: Make sure we don't have any MRIs.

Maxine: On scans, the magnets show up quite big.

Raewyn: We should be wearing our silicon bracelets or medic alert ones. (Both Raewyn and Gloria have silicon ones – but don't wear them ... hmmm).

Stuart: I heard about CICADA a number of years ago and get the newsletters. I wanted a copy of the book and thought I could pick it up at the forum (the launch was the same date). I didn't realise it was in Australia.

Donna: Some of the books on CICADA I am enquiring about getting copies of.

Laurie: 2 years ago I changed doctors – my old one retired. He didn't know anything about CIs.

Stuart: If your CI falls off, no one knows you have one. I have a medical alert and it costs an annual fee and the initial form needs to be completed by your doctor.

Maxine: Stuart you have some skills. You should help run the group.

Stuart: I found out about CICADA from John C when the social group was running at Carrington. It was in a pub, however it was noisy and one particular day a lady was singing and it just sounded like cats caterwauling.

Laurie: How often should we change our filters?

Stuart: The recommendation is every 3 months.

Donna: However I didn't change any for 2 years. It depends on whether you work in a dusty environment.

Raewyn: I noticed a huge difference in the clarity when I changed mine.

Vince: I lost my magnet. Simon (Cochlear) said I could wear a bandage until a new magnet arrived. When I went to the club, everyone wanted to know what had happened.

Donna: In the early days, I remember going to the university and Ellen said I had a donut on my head. This is because the magnet is too strong. Having been given a lighter one, it fell off in the early days until I got used to it.

Raewyn: I remember I got a donut also.

John: I play tennis and the processor falls off. I was told I have sensitive skin.

Stuart: You can alter the magnet to 'stick' better by slightly turning it.

Donald: It would be better to probably get a sports headband from Rebel.

Maxine: It would probably look cool as well.

Stuart: I wear a baseball hat which covers my ears when I am walking.

Laurie: I wear a hat also.

Raewyn: Reid Technology has those bandage-type headbands.

Maxine: With a hat it can be a bit annoying as the CI moves away from the magnet and continuity of sound is not guaranteed.

Donald: When I played tennis, the CI was the last of my problems. I couldn't play tennis very well ...

John: Which processor do I have?

Donna: Should have an N6 because you have been recently implanted. Read your manuals.

We continued talking about our surgery and some experiences and the casual meeting closed at approximately 12 noon.