

Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 15 August 2015 at Hearing Association, Remuera, Auckland.

Hosts: Di and Laurie

Present: Donna, Nic, John C, Gloria and John, Louis and Gabriel, Des and Gay Brown, Rodney, Kerry, Lyn, Vince, Pam, Diana and Fred Houtman, Marian, Anita and Frank.

Absent: Karel, Maxine, Zeta and Ged, Kathleen Bennett, John S, Jorgen, Raewyn.

Donna opened the meeting by welcoming everyone. It is with sadness that Virginia contacted Donna and wished to be taken off the email list. She is moving to Taupo. If people move out of the area – they are still welcome to receive the minutes and any information as the more people who are informed the better. Virginia was instrumental in helping set up the Auckland cochlear meetings in the early days. We wish her well.

A popular news item which went around the world shows a Taupo father having a cochlear implant tattooed on his head to support his daughter. Here's the link http://www.nzherald.co.nz/lifestyle/news/article.cfm?c_id=6&objectid=11492870

Recent information from news items is that cochlear implantees have been added to the free list for flu jabs. Here's the link <http://www.stuff.co.nz/national/health/70722428/flu-at-epidemic-levels-as-number-of-cases-soar>

The Waikato group meeting is going to be held on Monday 24th August at the Hamilton RSA, 50 Rostrevor St, Hamilton at 10 am. Anyone is welcome to attend and there is further information regarding other regional meetings available on the Pindrop website under next big event. Here's the link: <http://www.pindrop.org.nz/>

How many people have read processor and remote manuals? This question was put to our members and it was pleasing to see all hands raised. However whenever a problem cropped up you would probably only need to read the relevant information.

The list that was sent out to new members regarding information on processors and reading material has been changed to include information for the microphone filters. Discussion ensued and the recommended change time is 3-6 months. However some members had had usage for 18 months before needing to change. This is all dependent on whether people are working in dusty environments. It is up to the individual to work out when these need to happen to retain hearing clarity. But you need to be aware that you need to set up on a table and keep an eye on these small items. It may be 'fun' trying to find a filter if you have dropped it on the floor.

On the recommended reading list, John S says read the book: Katherine Bouton - Shouting won't help: why I – and 50 million other Americans – can't hear you. He said he was able to understand Marian's hearing loss. He would recommend this to all partners of hearing impaired people.

Nic from Pindrop said we needed to do another mail out to Members and Ministers of Parliament. Even though we have funding happening, it is an ongoing process. With this in mind by having the personal contact and stories, there is more impact – so we all need to send our letters on/by Monday August 31. Nic is to send information to Donna to mail out to everyone.

When people go travelling, equipment required generally related to the 'spectacle' case and disposable batteries. Some members in the early days had taken the dehumidifier unit and also the charging unit.

What telephones do people use at home both landline and mobile? Donna uses an analog dial telephone. However if requiring a press 1 or press 2 option she uses her portable but is unable to hear on it. This is an exhaustive process. She has been to Life Unlimited but found a number of phones which had the volume control did not actually work with her CI. Di uses a Phonak. Kerry uses a Panasonic portable. Lyn uses a Uniden or Panasonic portable. Di tried utilising a cordless in Australia when visiting and found it too hard to hear. Anita had tried a demo model and they wanted to sell her the newer model. When she took it home she found the newer model was no good. She tried the demo (older) model and had to negotiate with staff that this was the best solution for her – however they didn't really want to sell it to her. When purchasing a telephone – it may work well in store. However when you get it home it does not suit the situation. There is a lot of trial and error to get the best solution. Perhaps asking staff if you purchase can you bring it back within 7-10 days and get money back. Donna has a basic cellphone and uses the speakerphone. However this is not 100%.

Donna had previously asked Gloria to tell us her story which was shown on 7 sharp earlier this year. John her hubby got up. He said Gloria was privileged to get the implant and now the both of them want to help get information to others. They had noticed a number of people approached them and said they recognised them. Gloria has had hearing problems from birth. The right ear went first and 3 years later the left ear. Gloria was put onto the waiting list and after 3 years finally achieved success. The story on 7 Sharp was made because it was hearing week and they had been approached by Pindrop Foundation. The story showed Bill Barber who has been a surgeon for 30 years operating. 1 hour after starting surgery, the implant is placed in and tested. Then switch on day. After 10 mins Gloria noticed improvement and wanted to hear her knitting needs and birds. They had been taken to the Auckland zoo to hear the birds. The emphasis at the end of the news item was on the long waiting time for others on the list.

Gloria got up and spoke and said when switch on happened she didn't know whether to laugh or cry – and ended up wearing a huge grin. She loved hearing her grandson play the piano and talking and hearing what everyone says. Yes, her knitting needles now click – which is great as she could never hear them.

One day in The Warehouse she had a tap on her shoulder. Someone thought there was something on her hair. She explained about the implant and the person had never heard of it. They had grandparents with hearing problems and were going to

tell them about it. One other thing Gloria wishes to hear is the snow crack and that's on the plan to go on a cruise to achieve.

A suggestion was made to invite Jonathon Coleman (Minister of Health) to a meeting.

Pam said she had heard about a 100 year old in America getting an implant. Age is no barrier. Also Pam had been to the movies recently and found it a great experience.

Lyn got up and talked about safety. A Tauranga member recently had a stroke and was disabled by it. Lyn suggested teaching a family member how to put a processor and batteries together and how to place it on her. Her daughter has made a short video on her smart phone in case she forgets how to do it. This has raised a very important safety message as we cannot rely on the health professionals to know how to work our gear. A recent news item about a lost hearing aid created antagonism amongst members as at the end of the item they tried to highlight the fact that large value items should not be taken to hospital. One person who had been in hospital was wondering why they could not hear and it was the hearing therapist that realised that they needed new or more batteries. Obviously for hospital admissions disposable batteries are best. Perhaps a card with a phone number for the university to explain. However it is best that we make these plans before these situations arise. Also too as you are lying around a lot in hospital that having a head band is recommended to help keep your processor on. Also it is a visual alert to staff. Pam said we needed to know how to work our processor in case our remote goes missing.

It is important to identify any of these safety measures and have solutions in place before they happen.

John C talked about the N6 processor as there being no delay in pick up on the telephone as they are Bluetooth enabled. He uses the remote for volume and has found that clarity is 100%. However you need to change it to telecoil and have a special programme in your processor. Donna had information supplied to her from Trish at Life Unlimited regarding CIs and mobile phones. A lot of her information was from Penny Monteath in Christchurch who is a bilateral CI and is a hearing therapist. She uses one of these: http://www.tecear.com/Noizfree_Mobile.htm

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- Can you describe exactly how you use it with your CI? You place the hooks behind your ears. Doesn't matter whether they are in front of or behind your hearing aids/processor, just wherever its comfortable. Activate your telecoil
- Which Processor do you have? I have an N6
- How effective it is with an N5? It will work with any model of processor or hearing aid provided they have a telecoil function and that it has been activated!
- Does it cut out any other BGN i.e. reduce the user's awareness of the environment, what is going on around them – this would be a minus. If you have an option for MT (microphone/telecoil) then you will hear whats going on around you. If you have telecoil only, you won't. MT option is definitely available on processors and I'm pretty sure all hearing aids can be set up this way if necessary as well. Its all in the software as an option.
- My understanding is that it may not work with a basic Nokia ph, it needs to be a Smart ph or I ph? It will work with any phone as long as there is a headphone socket to plug it in to. You just need the additional connector if you have an Iphone/smartphone. You don't need this if your phone is an old model.

John C also said we could clean our processor. You could either use warm water – however he utilised isopropyl alcohol once a month. This is important as small amounts of dust may accumulate. If anyone had a Freedom processor – the filter could be cleaned by washing in warm water.

Pam had ordered some My tiny reminders and had a few left over if anyone was interested in purchasing.

The meeting closed at 11.30am and members continued discussion until 12noon.