

Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 15 October 2016 at Hearing Auckland (Hearing Association), Remuera, Auckland.

Hosts: Gloria and John

Present: Donna, Kerry, Raewyn, Maxine and Sue, Laurie, Glenda, Lyn, Vince, Louis and Mona, Des and Gay, Anita and Frank, Stuart, Nic.

Absent: Di, Zita and Ged, Pam, Diana and Fred Houtman, Linda Piggott, Michael Lee, Caroline, Belinda Sperling (Tauranga), Raewyn Ashdown, Rod and Helen McAlpine, Rodney.

Donna welcomed everyone and thanked to Gloria and John for morning tea.

As Lee Schoushko has been at our last meeting, some members did not know who or what he represented. He is a NCIT (Northern Cochlear Implant Trust) chief executive, Pindrop Trustee and Chief Executive. Also recently on the Auckland Hearing Association's board.

John and Gloria had purchased some waterproof zipper bags which came as a 5 pack which are useable for up to 10 times. Anyone wishing to purchase a single unit, contact them.

Kerry last month mentioned some new smoke alarms that had come onto the market. Karel said the new system came from the UK which was a Bellman unit which had more components. With the current system, batteries need to be constantly replaced.

Donna suggested to all members who had smoke alarms to check the little push button unit (approx 2.5 inches by 2.5 inches 10cmx10cm). She had been alerted to the fact that if this unit did not have batteries operating, the whole smoke alarm would not work. When she had received her smoke alarm nearly a year ago, she had found after a few months the battery which was meant to last 5-10 years did not work. Upon replacement the unit was working once again. Please remember to check your strobe/clock to make sure the vibration pad cable is still attached. She had pushed the strobe to test it and found the pad cable had disconnected when it had fallen down.

Donna, Vince, Raewyn and Kerry manned a stand at the Pukekohe Ageing Expo recently at which we have been represented for approx 5 years. Raewyn had never attended before and said she was surprised at how big it was. Approx 100 stalls which were close to each other. Information displayed about Pindrop got people asking what it was about and that people didn't know about CIs. The pamphlets on display 'when hearing aids aren't enough' produced by Pindrop are an excellent resource and these are greatly appreciated by attendees to read later.

SCIP has released advice about social media and online forums. This is useful to utilise alongside information received from your clinical team and to realise that some advice dispensed may be misleading.

<http://scip.co.nz/wp-content/uploads/2016/09/Internet-Forums-and-Patient-Advice.pdf>

A new processor which does not need to have a hook or sit over the ear has FDA approval. This means if people have problems with glasses as well as their processor, this may be the solution. Here is the link:

<http://www.audiology-worldnews.com/market2/1759-cochlear-receives-fda-approval-on-new-hearing-device-kanso>

Simon had sent an email to the club advising that the NZ online store is available from 17 October. You will need to register and all your details regarding the colour and processor are in the system. Here is the link: www.cochlear.com/au/mycochlear, and attached is the flyer for details.

Des and Gay had sent a newspaper clipping from the North Harbour News in which a family of 4 children, 2 had cochlear implants as a result of a recessive gene which causes hearing loss. Attached

The Hamilton group has sent a newsletter from their recent meeting. Ngaire has given up leading the group and Cabby has taken over until someone else can be found. Attached is more info.

On trademe Donna found a newly released book which is about an American woman who was deafened at age 6 and received a CI at 67. Called Coming to my Senses by Claire Blatchford she has asked Auckland Library to purchase a copy. They have decided to buy two.

Louis came to the front to talk about his recent surgery and switch on. He was operated on on August 25 (7 weeks ago). Switch on was 4 weeks ago. It was very exciting and he has recently heard birds. When people are speaking it is still a bit hard. He uses a hearing aid in his other ear and the two together are hard and create a bit of fun. He thanks the team for their help both from the university and the Auckland group for their support. He has been on the waiting list for approx 2 years and knows some people wait for longer. He understands that the priority is for people who are working or have children. He thinks the seniors have a lower priority. Recently when in an aeroplane and it was landing he lost sound completely and found it came back approx 5 hours later. Even up a mountain approx 2000m high he found he lost his hearing again. He was reassessed and put up the list. He said people on the waiting list need to alert the University if they are having problems. He has one ear that uses a hearing aid and the other has no hearing. The University team decided to implant his non-hearing ear and they all realise it will take longer. He said they are the professionals and they told him what was best. Apparently the internal structure in the non-hearing ear was able to be used for a CI. With the processor he hears lots of beeps initially and then birds. He picks up lots of words and feels he is progressing well. He knows there is lots of training involved. He feels he has the power to face challenges now.

Lyn said she had been to a recent conference and talked to a lady from the USA whose daughter is thinking about getting a CI. Lyn thought it was interesting that a NZer was telling her about the process. Fortunately she had taken the Sounds of Silence book with members stories and gave the lady a copy.

Donna, Lyn and Apii from Auckland attended the Pindrop Photo Exhibition at Tauranga recently. On the Friday night approx 70 people attended and on the Saturday approx 55 people which most attending in the morning. A newspaper clipping about a Tauranga member who is being followed for a year before and after CI notified people about the exhibition. Here is the link

http://www.nzherald.co.nz/bay-of-plenty-times/news/article.cfm?c_id=1503343&objectid=11713374

From Tauranga, Josie and Aynsley have started a facebook page www.facebook.com/groups/cochygroup/ And also an email cochygroup@gmail.com

Nic talked about how National MP Simon Bridges attended on Friday night to open the event and it was great to have Josie, Aynsley and Charlotte all attend. She was pleased with the great turnout.

The forum is being held in March 2017 and Frank Lin, an international speaker is available to talk about the ageing aspect and how access to CIs make a difference to people's lives. More information will be presented at next month's meeting.

Donna introduced our guest speaker David Welch, Head of Audiology, Auckland University.

David apologised because the computer and projector were not working in conjunction with each other and he was not able to display information.

A CI creates interesting challenges. Each ear is different and sound on the left ear is not heard in the right ear. The ear shape also alters how people hear. If sound is from the front, it goes in directly whereas sound to one side comes from a different angle. The ears cannot use the same clues.

A recent project using a CI in conjunction with an acoustic hearing aid, said the 2 sources make the direction hard to judge.

As a number of people have only one CI, with training people can get better direction-wise. They have done a thesis where people were put into a room with lots of speakers in different directions. He said some people found they needed to move their head to one side to hear it. He said the human brain is extremely adaptable. And people can improve their performance with the training. However he said it was better to train and then sleep because while you sleep the neurons grow. Training then listening had not given the brain time to change.

Cognition – this is a field in which Frank Lin has done numerous studies (he is the main speaker at the Forum 2017). Especially with people who have dementia. With this disease, the ability to think disappears when their hearing goes. Hearing is needed to help with the ability to think.

David gave the example of the brain being a predator needing to hunt and capture information. If the hunting is poor, and gets no meal, he is weak. The brain is getting no

information, and becomes weaker. With the hearing loss – the weakened hunter has to work harder and resources are fewer.

A group of CI people and people on the waiting list were tested on their cognitive ability. Four tasks on similarity (spoon, fork), general knowledge, memory and arithmetic, people with CIs performed better. However when there were 3 tasks involving patterned blocks, picture completion (what's missing) and symbol coding (star = 1, block = 2) with unusual shapes, both teams performed the same.

Working memory retains 7 pieces of information at once. The magic number is 7 + or minus 2. So some people can retain up to 9 pieces.

The difference between the two results was that because the first 4 tasks were spoken, the waiting list clients were using all their energy hearing speech rather than hearing what was actually spoken. Their memory was used up listening and their mind was tied up trying to listen.

Raewyn said she used to say to her nephews that she couldn't understand things, so couldn't remember.

Donna said she remembered being introduced to people and spending all the time trying to remember their names – when in fact she had never heard the name at all.

David said this came down to comprehension.

Lyn said that some people who are lateral thinkers throw this theory out.

David said we needed to stamp out lateral thinkers.

As a result of being on the waiting list, physical health can deteriorate. As soon as the symptom of hearing being a problem is removed, these issues are resolved. When people find out they are near the top of the waiting list, but others go in front of them, this can be a constant source of stress and anxiety. He said it was a bit like voodoo where you get someone's hair and put it on a doll and then push pins in. It is a psycho neurological thing. If you believe or feel there is something wrong, you can make it wrong. Stress gives health problems and this is where people can end up with psychiatric, anxiety, infections, arthritis, hypertension, diabetes, colitis, etc.

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The below information has been supplied by David as Donna could not keep up:

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|-----------------------|--|
| • Psychiatric | depression, anxiety |
| • Immune system | infections, rheumatoid arthritis, asthma |
| • Cardiovascular | hypertension |
| • Endocrine disorders | diabetes, thyroid problems |
| • Gastrointestinal | colitis, IBS |
| • Pain | migraines, musculoskeletal pain |

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People who are on the waiting list are struggling they suffer for longer and their immune system is suppressed. While they are waiting, they have a need for more medication, however once the CI is received these health problems disappear. This is a huge thing the government needs to consider.

Another study has been on support people of the hearing impaired. These people take on the role as a channel and has a huge impact on partners before CIs. These are with communication difficulties and sharing emotion and intimacy. Things for a support person relate to talking in simple ways and the reliance on the support person increases as the hearing loss gets worse. Lots of relationships break down as their partner needs them to be practical and frustration overtakes the loving environment.

Karel said it is not nice when people shout and have an angry face.

David said it is unfortunate that some partners end up with a hectoring nature (bullying) and talk in not nice tones. They get angry and frustrated with the person with hearing loss.

Karel said it can change the partners. He knows of one lady who shouts at her husband and when out in public does the same thing as it has become ingrained. People who can't hear do not want someone shouting at them all the time. He is in a group and feels this is affecting them all.

David has parents who are having hearing loss and his mum now wears hearing aids.

Donna said she found after having her CI that her parents talked louder to her. She noticed this when nephews and nieces visited at the same time and found they were spoken to at a lower volume.

Laurie had problems within his marriage and at one stage told his wife she could go.

Donna said it was hard not knowing when you put yourself in an unsafe situation (when deaf). This could reverberate on their partner hoping you weren't putting yourself in these situations unintentionally.

David said the situation regarding hearing loss was best described by having been out on the booze the night before and waking the next morning with a hangover wondering what you had said and who you had offended.

Karel said he was now a minister of the church and was running a group in the early stage of dementia. He said he had found a member had received hearing aids and their life had changed and the dementia label was taken away. Also another person who they thought had early stage dementia and was disorientated had an operation and they had changed also.

Donna said this would be difficult for GPs to diagnose. Obviously if you are given a dementia label, it needs more discussion about what could be the original source of the problem.

David said Karel should probably keep an eye on people in the group and be instrumental in organising help if required to find the source.

Raewyn said that she found that when she couldn't hear she felt shut off and confused.

David had recently been to Rio and found the foreign language had hints of understanding if you listened carefully.

He thanked all people who had participated in the studies and this helps provide information which can be produced to show Government officials the impact that hearing loss has. In the long run this will have a wide impact and help others.

Donna said that looking back before a CI it would be very difficult to participate in studies. It is a hugely emotional and challenging experience.

David said that by gaining access to a CI, lots of problems are corrected.

Donna said that she uses the expression that before a CI people use 100% of their energy to listen. And to keep telling people every day that you are having problems, people think you are boring and don't take notice. This is where because the disability is invisible, people think you don't have a problem.

Karel said that the loss of hearing is a type of dying.

David said they are now doing workshops in schools and workplaces on preventative noise loss. He himself has a hearing loss as a result of listening to loud music.

Lyn thanked David for his time. Lyn said that when you are deaf, you tend to accept that that is just how it is. She remembers the first time she was standing on the steps outside the university and heard cicadas.

The meeting closed at approximately 12noon.

Next month is our final one for the year. With it being near Christmas, can people bring along Secret Santa gifts to the value of \$5.