

## **Auckland Cochlear Implant Consumer Group**

Minutes of the meeting held on 19 March 2016 at Hearing Auckland (Hearing Association), 8 Vincent Ave, Remuera, Auckland.

Host/ess: Laurie and Di.

Present: Donna, Laurie, Di, John C, Karel, Maurice and Patricia Hansen (Whangamata), Zeta and Ged, Gloria and John, Stuart, Kerry, Anita, Maxine, Bernadette (Christchurch), Donald, Rod McAlpine (Te Kauwhata), Lorna.

Apologies: Lyn, Vince, Nic; Louis, Mona and Gabriel Ho; Des and Gay Brown, Pam, Rodney, Marian and John.

Donna opened the meeting by welcoming everyone to the meeting. Thanks to Laurie and Di for morning tea.

Welcome to CI visitors to the club:

Rod McAlpine (Te Kauwhata) friend of Donald who had his switch on at the end of February 2016. His wife is Helen (a nurse) and he is in his early 70s. He has been deaf for the last 25 years relying on lipreading and hearing aids until they were of no use.

Maurice and Patricia Hansen (Whangamata). He was implanted late last year. It was great they made the effort to come to the meeting.

Bernadette (friend of Maxine) from Christchurch. She is a hearing therapist and has had a CI for 11 years.

The email for Zenipower disposable batteries which was sent out on Friday does not apply to NZ products. The recall related to batches supplied to the NHS (National Health Service) in the UK.

Remember CI people are eligible for free flu jabs.

Here's the link: (This is detailed at the bottom under VACCINE DETAILS):

<http://www.stuff.co.nz/national/health/70722428/flu-at-epidemic-levels-as-number-of-cases-soar>

Topic for discussion was dispersal of club funds. Currently we have an excess of approx \$150 and discussion at club level was required. Suggestions included door prizes or perhaps donating to other hearing services (Pindrop, Hearing Dogs, Hearing House). Donna said we were extremely lucky in that there is no charge for the use of the rooms for our meetings.

Karel talked about how Pindrop does a lot for CI people. The SCIP (Southern Cochlear Implant Programme) deals with people south of Taupo. The NCIP (Northern Cochlear Implant Programme) deals with people north of Taupo. As they are a trust, they needed an independent entity which is where Pindrop has come in and they are able to advocate in conjunction with consumers. The NCIP gets the funding from the government and has to manage it so that as many consumers are implanted as possible (with allowance in the future for upgrades, etc).

John C said he wanted a door prize for each meeting. As members had donated the money, we should keep it for ourselves. There are expenses for sundries (tea,

coffee) and also a gift for guest speakers. At Christmas time a morning tea funded from donations each year is anticipated also.

A number of members said that the surplus was not large and we should sit on it for a bit. A suggestion of opening a bank account was put forward. When funds increase to perhaps \$300 or \$500, we can address the issue then.

At our last meeting, Neil from the St John 111 Centre suggested we could visit the centre. It is situated in Mt Wellington and groups of 10 or less are recommended. Di, Zeta and Ged,, John C, John and Gloria, Donna have put their names forward. Donna will organise a Saturday and get back to members.

Members were made aware that the traffic camera centre in Smales Farm on the North Shore could be another place to visit. John C said he had been there and had seen a hitchhiker being picked up and also what action was taken when a bus broke down at an intersection.

However St John Centre is our focus currently and this can be decided upon later also.

No talking during our guest speakers presentation. If you must talk – take it outside.

Donna noticed recently that watching Prime there were programmes with subtitles. This was awesome. Someone had gone to a motel and found they couldn't work out how to get the subtitles. Lorna suggested that when you book accommodation, you ask whether the TV has subtitles. Di said a lot of the televisions were newer so they should generally have them. Donna has found previously that different decoders, i.e. Sky, freeview have different applications. Sometimes you can use the remote for the decoder to get subtitles, but other times the TV remote is what is required.

Zeta had given Donna information about a website which has movie screenings throughout NZ which have subtitles. Here is the link: [www.captionmovies.co.nz](http://www.captionmovies.co.nz)  
Click on session times and other movie options are available.

Recent newsflashes.

<http://www.stuff.co.nz/taranaki-daily-news/news/77159881/cicadas-hard-to-listen-to-for-new-plymouth-man-who-has-his-hearing-restored>

Cicadas hard to listen to

[http://www.nzherald.co.nz/lifestyle/news/article.cfm?c\\_id=6&objectid=11598069](http://www.nzherald.co.nz/lifestyle/news/article.cfm?c_id=6&objectid=11598069)

Tattoo behind ear showing deafness

John C said he had fallen asleep while watching TV and found that when he woke, his processor did not work. He has never had a replacement coil in the 18 years he has had a CI and found this was the problem. A suggestion was of having a spare on hand, however at \$300+, you can alert the Auckland University and they can loan you one until a replacement arrives.

Di and Donna have had a replacement coil within 3 years of having their N5.

Di said that she had recently had parts fail. It ended up being the holder for the disposable batteries. She had borrowed items from the Auckland University to try to

isolate the problem. When she used a different cover to the unit, she found the problem. We need to talk to the university and seek help when required.

Donna handed over to Karel with a question from Lyn. She said she found that if we listened to music we knew before hearing loss, do we fill in the gaps, i.e. our processor may not pick up everything? She had found listening in church that she had to listen carefully to pick out different instruments and found gaps.

A number of members had found the same thing. However we need to utilise our ability to listen better.

He said that he was told that people with a cochlear implant can't learn new music. However he played the same tune on his piano for a number of times and found he could, however it was different. We should all be grateful and thankful for what we can hear with our CI.

Donna said that the CI was originally produced for listening to speech and if we get music, its a bonus.

Karel said the N5 has a music programme and for music listening it is best to use it. John C has an N6 and the programme changes automatically for optimum benefit in different environments. TV listening is perfect.

Lorna said the N6 is amazing. As an orchestral musician, she hears fully. This is mainly for music she has known and finds when learning new music, it can be painful. (Lorna has 2 implants).

Di said she listens to church music and understands it but sometimes doesn't know when the end of the line comes.

Donna suggested that we revisit listening skills. As we progress with our hearing, we can get a bit complacent about what we hear.

Lorna said with this in mind – we need to push our boundaries.

Karel found listening to Country and Western music for a while, he found it came alive. Persistence is the key.

Di said we need to challenge the boundaries as we become too comfortable with what we hear.

John C said when he first got a CI 18 years ago, he heard no music. However with the advance in technology with the N5 and lastly the N6, music listening ability has progressed massively.

Karel said we need to pay attention and understand how the brain can process things. A suggestion of going out into your back yard for 30 minutes and listen and look and focus. You may see and hear things you have not noticed before as they are familiar.

Hearing Auckland had a piano and Jonathan had brought along a keyboard and amplifier. He changed from one to another and a number of people could pick up the difference. The piano had a persistent background hum because of the pedal being held down and the keyboard was a bit scratchy because of its electronic sound.

Sheets of words for singalong were passed around.

The first song 'Amazing Grace' was sung. Jonathan was pleasantly surprised that we could keep a tune.

Karel asked Jonathan what he thought of our singing. He said it was 'agricultural'. The girls sounded good and the boys sounded ....

Lorna had been a soprano singer and found she was now a tenor singer.

'You are my sunshine' was next and Jonathan said we sounded good. He suggested also that we sit at the front of our seat and instead of just using our mouth to sing, to utilise our lungs.

'Silent Night' sounded much better because we were getting into the rhythm of singing.

'Wonderful World' and then we tried a canon where we sing in 2 different groups. 1 group sings the first line and then the 2<sup>nd</sup> group joins in singing the first line through to its end. It was only 4 lines but had a distinctive beat. Jonathan was holding his hand and moving it up and down to show different pitches and this helped some members.

'Amazing Grace', 'You are my sunshine', 'Silent night'.

Laurie asked if we could sing the teddy bears picnic.

Karel said he noticed that at first the piano had a 'wow wow' sound.

Bernadette said we need to listen to one instrument at a time. If listening to an orchestra – check which instrument is playing.

Donna thought the piano was easier to listen to. Jonathan said because as the piano has a large range, this could be the reason why.

Karel said he found the flute better.

Bernadette said she found base music easier and had initially found she had lost 2 octaves on the piano.

Jonathan then played some new music. It has a background beat with little tinkly sounds at varying intervals. He was interested in what we thought of it.

Members found it to be meditative and calming.

Maxine said she found listening to music from the 60 and 70s that the beat made it easier to listen to.

Di said if we should continue to listen to music to get the rhythm and beat we will eventually 'get it'.

Donna said that she had read that the loss of music when people become deaf can make them depressed. Our body relates to different levels of vibration and that is why when we sing we have the 'feel good' factor.

Bernadette found it was hard to tell up and down tones. She also finds it hard to understand foreign speakers as they change the beat of their speech.

Zeta thanked Jonathan for his presentation and presented him with a gift of our appreciation

Donna then told members that at our next meeting we have Simon from Cochlear and to bring lots of queries/questions for him to answer.

The meeting closed at approx 12 noon.