

## **Auckland Cochlear Implant Consumer Group**

Minutes of the meeting held on 20 August 2016 at Hearing Auckland (Hearing Association), 8 Vincent Ave, Remuera, Auckland.

Host-ess: Louis and Mona.

Present: Donna, Kerry, Vince, Marian and John, Nic, Rodney, Laurie, Karel, Glenda.

Apologies: Caroline, Stuart, Zeta and Ged, Anita and Frank, Rod and Helen, Raymond Fraser, Maxine, Des and Gay Brown, Raewyn Ashdown, Pam, Raewyn.

Donna opened by welcoming everyone to the meeting. Thanks to Louis and Mona for morning tea.

Welcome to Glenda who is attending for the first time. Jacqui from the University of Auckland had told her about our group.

Awesome news for Louis who is getting his CI implant next Thursday. Exciting times ahead for him.

When you have a comment at meetings, please make sure you stand up and face others so that we can hear / see you. We need to remember when we couldn't hear. Also too it is difficult to note take when you are unable to see the speaker.

The Auckland University is doing trouble shooting between 1 and 1.30 Monday to Friday and no appointment is necessary for this service. Mapping needs appointments.

Live captioning at Parliament from August 10 meant Mojo is able to follow the debate from her office.

<https://blog.greens.org.nz/2016/08/10/live-captioning-for-parliament-a-major-milestone-for-democracy/>

Nic said a new development for Parliament is that if you have a smartphone all members are listed alphabetically and are able to be contacted. You could contact your local MP for more TV captioning. Rodney said that if you get Netflix – every programme is captioned. (Monthly charge on top of broadband network). He has had Sky for 15 years and only a few programmes have subtitles.

Nic said in the United States – subtitle accessibility is a legal requirement. Also if people are developing a website the need to use big fonts.

When in Britain a prescription showed Braille usage.

Rodney said DVDs also have a legal requirement to have at least English subtitles. This was a law passed over 20 years ago. As 1 in 6 people have hearing loss they need to be catered for.

John thinks Sky will disappear.

Nic thinks if people know about Netflix having subtitles, they will get more subscribers. Also people can access internet TV.

A recent news update about a British CI double recipient who has been viewed on You Tube having switch on. Jo Milne who has usher syndrome is now going blind. Please note her book is available from the Auckland Library and she had been employed in the disability advocacy community.

<http://www.stuff.co.nz/life-style/well-good/teach-me/82681047/a-woman-who-became-able-to-hear-is-now-going-blind>

Recently checking out the Southern Cochlear Implant Programme (SCIP) newsletter has found that prices for accessories is cheaper than Auckland University. Examples are rechargeable battery \$293 against \$332. Battery holder \$180 against \$202. Also don't forget to check out Cochlear own website or 0800 number (0800 444 819) or email customerservice@cochlear.com. In the future accessories may be available via the Cochlear online store (currently only Australia). Also for dry bricks or dessicated moisture blocks – these may be available cheaper from an audiologist. It may pay to shop around.

Marian also suggested that for disposable batteries to shop around audiologists also.

Marian is also having problems with her dehumidifier box. The wire connection to the box seems faulty. She has talked to a few people who got theirs at the same time and perhaps there may have been a faulty batch. John said the unit runs on 12 volts and they live in a 5 wheeler and their voltage is 24. An adaptor is required. Karel has the same thing with his caravan.

Donna said John and Gloria were living on a boat and they could not use the unit which had come with the kit. They had to revert to using the moisture blocks for drying her CI in.

The dehumidifier box gets hot after a while. This automatically switches off after a pre-determined time. You may need to put it onto a chopping block or a surface where heat does not cause a problem.

Laurie: How often do the bricks need changing.

Donna: recommended every 2 - 3 months.

However Di and Lyn have a silver unit which they use. (available from SCIP). They are put into the oven to dry out. However don't know how long these last.

Karel: The units increase in weight as the moisture is absorbed. Original weight equals 33 grams and increases to 38 grams.

Laurie said he had a wonderful experience recently. His neighbour across the road was talking to him and he understood him well. They ended up having a good conversation.

Also from SCIP Donna has made contact with 9 group co-ordinators and had 2 responses for information. Obviously some of their members are from great distances and email information keeps them informed.

Nic told us about the upcoming Sounds of Silence photo exhibition which is going to be held in Tauranga on 23rd (5-7pm) and 24th September (10am-3pm), The Historic Village, 17<sup>th</sup> Ave West. This is to promote the event to the Hamilton group also.

Pindrop is also working on the forum for 2017 which it is hoped will coincide with hearing week, which is the first week of March. There are discussions and planning underway and a survey will be sent out in late September for input into topics members want.

By the end of next week, the video launched at the Sounds of Silence will be available to view on the internet. This has taken time to get royalties sorted for the use of the music. It is a powerful short video featuring a CI users from different backgrounds, ages and cultures.

Donna said she had recently been in Tauranga and there was lots of traffic around 5pm. If anyone is interested in attending the Friday night event to allow for this.

Nic leaves.

Recently receiving information from Tauranga, a number of members are due for replacement processors. Lee is looking into this. (minutes enclosed)

Laurie is worried he may lose his processor when fishing.

Donna suggested wearing a hat or a head band.

Laurie doesn't want to do this.

Then the topic of insurance came up.

Rodney: what do we need to do.

Donna: The university gave you a sheet of paper which had the cost involved for a new processor. You signed it and gave a copy back to the university and a copy for yourself. This is so that if you require a loan processor, your insurance covers this also. Some insurance companies require this paperwork, or you just need to have it listed separately. A number of members said their insurance company did not require this procedure.

Also too that if you are going overseas travel insurance does not cover your CI. You will need a separate policy and this is extremely expensive.

Donna went and visited our old meeting site (Hearing House) before today's meeting. This is under development. The pre school is finished. However the area next to it is cordoned off. The house on the corner is still there, and the house next to it and the garage we used to hold our meetings has all gone. Donna will organise to book meetings where we currently are for 2017.

Rodney: What is the Hearing House.

Donna: This is where all children (0-18) are rehabilitated. They prefer to have children implanted at the earliest opportunity for the best results. Auckland University looks after all CI adults (19 onwards).

From May, a Country Calendar programme featured a CI recipient. He had used a shepherds whistle and thinks this may have caused his hearing loss. There is now a requirement that if shepherds use this whistle, they use ear plugs.

Is anyone interested in visiting the St John communications centre in Wellington. We need to have 10 and this will be held on a Saturday if people are interested. Please let Donna know.

Useless information. Donna had recently gone to a 'wings and wheels' local day. Police were on site showing off weaponry. As the use of the taser is more predominant, there are less side effects from its use. When a taser is deployed it constricted the muscles. So if you are a CI user, this will not impact on your CI.

When attending expos and making speeches, there is a CI demo model available which shows the processor, remote and implant. Donna had bought this along to show members. It is interesting to note the size of the cochlear coil and that the pindrop size of the 22 electrodes which stimulate the nerves. The other piece is put around the mastoid bone which is the bone behind the ear and works as an earthing unit. Members were extremely interested in this.

Louis said he had been looking online about getting a CI and he was frightened of the operation.

Donna said originally the scar was quite well into the hairline with a decent amount of hair removed. One she had seen was along the hairline. Hers is in the crease of her ear. Surgeons may do different incision sites – however there is a template as to where to situate the implant. Exciting times ahead for Louis.

Rodney: Initially there were lots of noises. One I couldn't track ended up being the microwave.

Marian: I enjoyed the sound of rain and the shhhh sound.

Everyone is different and we all have our own idea of how well or not well we have done. However we have had to work at it.

Louis was told if they implanted his right ear, the CI compatibility would be quicker and if they implanted his left year – it would take longer to pick up sounds.

Operating on Donna's right ear was the solution to having continual tinnitus. Both ears are the same hearing wise. After the operation there was silence – however the tinnitus returns at night when the CI is taken off.

Marian loved the sound of crickets.

Laurie could hear his wife snoring ...

Marian had had a problem keeping her processor on. She has a small ear. The university had tried a mould and hooks, but not satisfactorily. A solution has been found at a local hairdresser who deals with cancer patients and wigs. Toupee tape. This is applied to the processor itself and sticks to the side of her head and then it enables Marian to wear without a hook. This lasts a couple of days and is double sided.

Onto our topic of the day:

Karel uses an old eye shade container for his hearing aid batteries.

With spare rechargeable batteries, Donna carries hers in a plastic medical bottle.

Karel: You could put some paper in between the batteries. With the rechargeable batteries, there is the possibility of the screw top piece coming away from the main unit. With care this could be stuck back in. However there could be a weak point in the connection. Internally there are 4 wires of which 2 control the charge in and 2 control the charge out.

Rodney: I only have 2 batteries left (originally everyone gets 3). At night he leaves the battery with the processor. In the morning he takes the new battery off the charger and puts the old one on to charge. He does not keep it charged.

Karel: With the lithium ion batteries there are limitations in how they move. Batteries normally are charged up to 80%. Lithium can be charged up to 100% - use immediately. When it doesn't discharge – it becomes dud.

Put the battery on – turn off – turn on – and charge again. You can do this several times. When the battery beeps in your ear – that is at 35% of its power. Then approx ½ an hour later this is at 20% of its power. It would be best to put his battery on at night. Once the battery is below 20% of its power, it is designed to turn off.

Donna – the cochlear batteries need a lot of power. My thinking is it is similar to a microwave oven and an ordinary oven. The microwave needs its power instantly whereas an ordinary oven takes time to get to heat. With regard to disposable batteries, if you buy cheap ones they may only last 1 day, whereas more expensive ones last 3-4 days.

Karel has spent a lot of time investigating battery usage. He has only 2 batteries and has had his CI for nearly 6 years and gets 16 hours a day from each.

Laurie: I move my charging position each day and leave them on charge all day. How do you remember which position you have put the batteries on when you only have 2?

Karel: Clockwise for charge – anti-clockwise for use.

Donna: When going away on travel, I use disposable batteries. Initially I use to take the charging unit and dehumidifier unit but these are bulky. I use the case (like spectacle case) and a pack of batteries.

Marian: I didn't get one in my kit.

Donna: You could use a spectacle case.

Karel: I use a plastic klick klack container. I also take some spare parts.

Rodney: I have never had my CI trigger the alarms at the airport.

Marian: Normally they just use the wand.

Donna: That's fine so long as they don't wave the wand over your head. This may cause your maps to disappear.

Karel had a horrific experience in San Francisco before his implant when he was very deaf. He has a steel upper arm. On going through security, this set off alarms. He was with his wife and she was shooed away, and she was not allowed to help interpret. A junior officer had his hand on his gun as they thought he had a shoulder holster. A very tense situation. An older officer gave Karel a pat down and advised the young officer of no gun. He moved his hand away from his gun. Karel said he could see the fear in the junior officers eyes.

Karel explained that this was at the time that a shoe bomb had gone off in Paris and they were on high alert.

Donna had an experience at her local Pak n Save which humiliated her and she did not return for 2 months. This was also when she was very deaf. She had been walking around town and purchased items at a number of places. On coming out from PnS the alarms were set off. She could not understand what they wanted and tinnitus went sky-high. Security are not allowed to touch your goods or you. Donna tried to understand what they were wanting, but was getting frustrated at having this happen at the entrance where all the check out operators were and customers were passing by. Eventually it was decided to put the trolley through – no alarm. Donna walked through and set them off. She was wearing shorts and t-shirt and offered to remove them. Then remembered her top was from Kathmandu. Security tag removed – problem solved.

Marian: Shopkeepers can be the worst and not be helpful and aggravate situations.

Donna loves her CI in the fact that she is getting direct information. When someone retells you something – they are putting their opinion onto it and this can be translated as something different.

This went onto a discussion about members having partners going to appointments and being the statue when their partner gets the information. It's like 'hello – I'm sitting right here'. Comments about doctors and nurses being amongst the worst entailed. However there are some professionals that take the time and make it a good

experience. Any time we have one – we need to thank them for their consideration. This may help the next person they are in contact with.

Rodney had a situation happen when he went to the chemist and had tried to communicate with him. Luckily his daughter was with him and the information was passed to her.

Marian wants to have a t-shirt made to say 'I'm deaf not stupid'. When she told someone she was deaf they asked her whether she could drive. She replied that she was probably a better driver and more observant.

Karel: An article by Alan Duff is very interesting talking about disability. Just because you are in a wheelchair or deafness is your affliction – this does not make you a lesser human being. Here is the link to the full story: [http://www.nzherald.co.nz/Alan-Duff/news/article.cfm?a\\_id=977&objectid=11685357](http://www.nzherald.co.nz/Alan-Duff/news/article.cfm?a_id=977&objectid=11685357)

The meeting concluded approximately mid-day.