

Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 18 March at Hearing Auckland (Hearing Association), Remuera, Auckland.

Hosts: Des and Gay.

Present: Donna, Des and Gay, Vince, Kerry, Laurie, Pam, Gloria and John, David, Maxine and Raewyn A, Linda Piggott, Donald, Louis and Mona, John Neale, Di, Anita and Frank, Nic, Lee.

Absent: Lyn, Maurice and Patricia, Viv Welham, Caroline, Diana Houtman, Raewyn, Rodney.

Donna welcomed everyone and thanked Des and Gay for today's morning tea.

New members

As a result of making contact last week at the forum, John Neale attended his first meeting. Having been only implanted for a few months he found it great to interact with club members.

Also Linda Piggott who has been on our members list for over a year, has finally had switch on only 3 weeks ago. It will be great to see how these members will progress.

They both find it great to be able to hear again.

Free flu jabs

Remember all CI people are eligible for free flu jabs as outlined in our March 2016 newsletter. Here's the link: (Details at the bottom under VACCINE DETAILS): <http://www.stuff.co.nz/national/health/70722428/flu-at-epidemic-levels-as-number-of-cases-soar>

*"It is particularly recommended for pregnant women, as the vaccine offers protection to both mother and baby. People with Down syndrome and **those with cochlear implants are also now eligible for the vaccine.**"*

PLEASE NOTE: Once you have registered and included your mobile number, the next year you will get a text saying when it is available. Please feel free to print off the above link to supply information to your doctor.

Information

Thanks to Stuart for providing some information from the hearing loss help newsletter. Of note is the information about Zinc Air disposable batteries which says you should take the tabs off and let air for a few moments before using. Otherwise the life of the battery is lessened. Other information related to clear surgical masks

to make lip reading possible, types of hearing loss, ototoxic drugs, loop systems and using TENS machines for pain relief. ***This document is attached as a PDF.***

Di says she has mixed up the batteries and could work out which were the new ones and which were the used batteries.

Any information relating to CIs and accessories you come across, please let Donna know. There is a wealth of information out there and it needs to be shared amongst the CI community.

Events

Donna attended the Deaf and Hearing Impaired Safety Day on March 12 in Henderson. As there is a large Deaf community quite a number of police, firemen and ambulance officers sign. Two hearing dogs and their handlers were also sighted. Amongst information which has already been given at CI meetings, a Civil Defence brochure was picked up about what to do in a disaster. (No water, no power. No internet or phone, can't get home, have to evacuate, stuck at home). Mainly the information is to make sure you have a plan in place. As the previous 2 weeks had had huge floods, these brochures could prove invaluable. Please remember that if you have been registered with 111TXT, you could make contact via this service.

Contact with a police representative suggested that the number of people registered with the 111TXT is among the hundreds. Yes, it is possible that if you have a hearing impaired person in your family, it is reasonable to register family's mobile phones.

CI research

Donna had been contact by Ellen at the Auckland University to participate in CI studies. We need to make sure that we participate if we are able to as these statistics are vital in helping CI recipients in the future. Others in the group are helping with research over a number of visits also.

Pindrop Adult CI Forum

A newspaper article leading to media publicity about the Pindrop Adult CI Forum and Frank Lin's visit was on the NZ Herald website. This related to the link between deafness and dementia. Here is the link:

http://www.nzherald.co.nz/lifestyle/news/article.cfm?c_id=6&objectid=11810669

Lee: Did you like the forum?

Maxine: Yes, it was different and had great guest speakers and was really good.

Nic: Live streaming was done via facebook. Information on TV1 about a young lady waiting for an implant is to be put on the Pindrop.org.nz website. Also the live feed

and notes from the forum will be put up also. At the end of March, a film of the whole day will be available to view.

Lee: As well as the forum, Frank Lin had come to New Zealand 5 days beforehand and his visit meant he spoke to representatives of the Ministry of Health, Otago Medical, Wellington Medical School and Brain Research programmes. He has in the past been the Public Health sector.

Even though 8 workshops were available to visit, members attended 7. The other one was for professionals. As a result of having professionals at the forum, it meant it was an even playing field and CI recipients could converse readily.

A show of hands let us know that nearly everyone in the room had attended the forum.

Workshop 1: Frank Lin, David Welch, Leanne Ma

Donna had attended this and found that statistics used during research in which she had participated was on display. This showed before CI and after CI and one recipient had been followed for 6 months, 3 before and 3 after a CI.

Gay and Des liked that the smaller numbers at each workshop made them more intimate.

Workshop 2: Suzanne Purdy

Pam: This related to research about how the brain works in relation to a CI. Also that when you hear from one side – it relates to the other via the brain.

Di: Lots of CIs are placed on the RH side as this is the dominant side and people's brains cross over. Right handed people controlled the left side of the brain.

Lee: Normally the worst ear is implanted.

Di: The ear that is capable of the most stimulation seems to be best. Also we need to make sure that we support research.

Linda: I was implanted on the least hearing side.

Di: I am left handed and they have implanted my left side, so there are some anomalies to the above theory.

Des: I remember a number of years ago seeing Suzanne Purdy and helping her do research. This happened over a length of time.

Workshop 3: Stacey Butler C5 Cochlear.

Donna: Stacey told us to keep all our programmes (i.e. 4). She had recently been to the university and extra maps were deleted.

Di: Next time you go to the University, ask questions about this. Initially when we get our implant, we have enough to learn about. In the early days we have simple map processes and as we progress they become more complicated. One lady at our workshop did not know about the telecoil programme and this needs to be placed onto a map.

Lee: Didn't you receive a book about the processes, etc.

Di: Yes. But in the early days I was not ready. Also I don't absorb information by reading and prefer discussion. As I have become more familiar with how it works, I am able to read the manuals and understand more.

Workshop 4: Katie Neal, N6 Cochlear.

Maxine: Katie was really clear and spoke well. It was not technical. Did everyone know that has an N6 that there is a reset button on your remote. This is on the far left, a tiny button. Sometimes when you are pushing buttons, you alter things. By pushing this reset button, you go back to your original maps.

Lee: I will contact Cochlear to if we can have some workshops set up for both N5 and N6 and their accessories.

N5

Di: This needs to be in small groups. I found out about when flying I need an adapter to plug into the headphone socket. This is then connected to my processor direct and crystal clear sound is heard.

Anita: (On display is the aeroplane adaptor). They have female and male connections. Watching TV I can connect directly to the TV and also the processor. However you need to make sure you connect the cord which has the surge protector. By using this, you can lower the volume however this may mean your partner may not be able to hear it. The aeroplane adaptor is available from PB Tech for approx \$5. When inserting into the processor, you need to take off the battery unit. The flip switch is under the cord and is silver and flips from bottom up.

Donna: We found out about the longer coil cord. This enables you that when in the car, you can put the longer cord on from the coil and place your processor on the opposite ear. This enables you to get better sound around your non hearing ear.

Maxine: I have done this and ended up putting the phone up to the wrong ear.

N6

Di: What happens with an N6 processor to get best reception on an aeroplane?

Donald: You can purchase a processor which has a FM button

Maxine: As the N6 has Bluetooth compatibility, the mini mic will work.

Laurie: N5. I use headphones over my processor.

Nic: Email this question to Simon (Cochlear). The transmission may be infra-red.

Stuart: I use headphones and push the T Coil switch.

Donald: I was impressed with one lady who had two cochlear implants and seemed to hear everything very well from all directions.

Stuart: N5 and N6, you may need to change programmes.

Workshop 5: Chris Walsh and Sue Ellis:

Anita: This workshop was different to what I thought it would be about. It was interactive and we made videos.

Kerry: They wanted you to say what your top tip was, i.e .speak clearly and slowly. A video of Anita was on the Pindrop facebook feed. (*5 seconds of fame*)

Linda: (who was seated next to Lee) What is Pindrop?

Lee: Awareness via the NCIT (Northern Cochlear Implant Trust), however they are both separate identities. It must be a great name (Pindrop) as a number of other organisations are using this for their websites. Note: Pindrop.org.nz

Workshop 6: Angeline Slade

Donna: A lot of the information given is available via the Hearing Therapy website. This workshop would have been great for a new CI or hearing impaired person to know what is available.

Di: I was cross to hear that someone in hospital had CI problems. The medical fraternity do not come across CIs very often and it is up to the individual to make sure their needs are catered for. Take care of yourself.

Kerry: I found this to be a long seminar, however it was great to hear of the assistance and help available.

Di: Everyone needs to know they can access Life Unlimited services. This could have been shorter. Interaction amongst audience would have been great.

Workshop 7: Josie Calcott

Des and Gay: We really enjoyed this workshop and our workshop had John from the video. We found it really interesting.

Pam: We heard about Josie's journey. In my workshop was a couple who were finding out information for their daughter who may need a CI. Handed out was a card which shows all CI support groups and contacts. Also helpful websites. Attached as a PDF. Please note: Donna Smith's contact is not gamil – but gmail. Thanks David.

Other general business

Laurie found that going to help with a study at the Auckland University, he had a trying day. Travelling 2 hours in rain and arriving 5 minutes late, he would have appreciated a cup of tea and some carbs. When 12noon arrived, he could not concentrate.

Di: When we are helping with research we need to perform at our optimum level.

Di: At our N5 workshop, a one use only waterproof jacket was on display. Also available on the cochlear website are waterproof jackets which are for multi use. However for lots of swimming and watersports, the Nucleus Aqua works best.

International Cochlear Implant Day is on February 25. Donna and Di share this birthday along with surgeon Robert Gunn.

There will be a meeting in **April** even though it clashes with Easter. As we are a support group, there will still be members who are unable to go away.

Coming up in **May** Cynthia Brown-Mendes from Hearing Auckland will speak about how the Hearing Association has changed over time.

The meeting concluded at approx 11.45am.

Attachments:

Hearing Loss Help (PDF)

Support groups contacts (PDF)