

## **Auckland Cochlear Implant Consumer Group**

Minutes of the meeting held on 16 April 2016 at Hearing Auckland (Hearing Association), 8 Vincent Ave, Remuera, Auckland.

Host/ess: Zeta and Ged.

Present: Donna, Caroline and Heather (new from Expo), Des and Gay, Maxine, Vince, Raewyn, Pam, Gloria and John, Stuart, Karel, Laurie, Rodney, John and Marian, Paul and Barbara.

Apologies: Lyn, Kerry, Maurice and Patricia, Mike and Evelyn Lee, Anita and Frank.

Donna opened the meeting by welcoming everyone to the meeting. Thanks to Zeta and Ged for morning tea.

Welcome to CI visitors to the club:

Caroline and Heather. Both had attended the expo last weekend. Caroline has had her implant for 6 months.

Barbara and Paul. Barbara is on the waiting list and has been on the email list for a while and this was their first meeting.

This year we have introduced a new meeting structure.

10-10.30 approx morning tea

10.30-11 approx information sharing

11am speaker

12noon approx finish

If anyone has something of interest that may take 3-4 minutes let me know beforehand to allow for its presentation.

Also if you know someone who could come along to speak – please let me know and I will contact them directly.

Luckily on Saturday last week, the NZ Herald had an article about the Taupo parent who had recently had a 2<sup>nd</sup> tattoo. Here is the link:

[http://www.nzherald.co.nz/world/news/article.cfm?c\\_id=2&objectid=11622213](http://www.nzherald.co.nz/world/news/article.cfm?c_id=2&objectid=11622213)

This was appropriate as 7 of our members and Simon and Jay Jay manned a stand at the Ellerslie Retirement Expo. Held Saturday and Sunday from 10am to 4pm this was a great opportunity to talk to the public about hearing loss. Everyone had a good time and Donna has possibly 2 speaking opportunities at clubs.

Another recent article talked about stimulating neurons in the brain. When we get a cochlear implant our brain has to translate the messages and the neurons have to fire and learn how to hear sound again. Here's the link

[http://www.nzherald.co.nz/world/news/article.cfm?c\\_id=2&objectid=11622187](http://www.nzherald.co.nz/world/news/article.cfm?c_id=2&objectid=11622187)

Gloria introduced our speaker for the day who was Simon Wilson from Cochlear NZ.

Simon loves hearing our stories and they are exciting. At the expo he said there was good interest from the public. However they still need to be told the CIs are not hearing aids and we need to explain about a CI and their benefits.

Australia has the largest number of implants per capita. 92% of all people could benefit from one – however they don't know about them. New Zealand has less than 3%. It all comes down to communication problems, i.e. GPs, Drs, etc.

At the forum last year – Jim Patrick, chief scientist in conjunction with inventor Graeme Clark says with CIs, their job is not done. They will continue to do their utmost to hopefully get as 'real' hearing as possible and with this in mind are always focusing on having the best leading edge technology available. They will not rest on their laurels.

The cochlear implant stimulates the nerves and the brain changes accordingly.

He recently had a lady in her 60s say she was hearing better than her peers, who were losing their hearing.

The 1<sup>st</sup> NZ recipient of a cochlear implant Florence Woodward has had her implant for 30 years and recently had an upgrade to the N6 processor. All throughout Cochlears history they have implanted units with 22 channels. Other brands originally started with 1 channel which did not allow for best hearing quality.

Youngsters who have not had hearing generally do well – so long as they are implanted early. With adults, the brain has to put the information back to create a circuit to get a similar sound to before hearing loss.

How many in the group had their implant more than 10 years? Maxine 21 years, Rodney 10 years.

In relation to other health implants people who have a hip implant are given a 10-15 year life before replacement is required. Also too pacemakers have to be taken out after a few years because the battery needs replacing. CIs once implanted do not need to be replaced and are there for life. In creating the CIs, it was imperative that recipients did not need more than 1 surgery. With this in mind, the implant does not have a power source. So this is what is called a passive device. The power source is from the processor which is external.

Recent technology advances has involved creating a single coil and microphone which is one unit and sits on the magnet. This means it is suitable for people who have small ears and find it difficult to keep on their ear.

Other excellent extra devices are the phone clip and the mini microphone.

Link to phone clip

<http://www.cochlear.com/wps/wcm/connect/au/home/discover/cochlear-wireless-accessories/phone-clip>

Link to the mini mic

<http://www.cochlear.com/wps/wcm/connect/au/home/discover/cochlear-wireless-accessories/mini-microphone>

Pam says she finds the coil cable from the processor to the coil too long for her head/ears.

Simon: There are shorter cables available in 5 colours and 4 lengths.

All processors are custom made in Sydney and Queensland. The remote assistant is made in China.

When surgeons are placing where the implant is to go – there is a template. This is to ensure that the best placement is available for both the processor and implant to do their job.

The N6 has a low profile cable and coil.

All implants are water resistant (within reason). They are the best in the industry. They are water resistant in 1 metre for up to 30 minutes (however ONLY with rechargeable batteries).

Do not put your processor into the microwave for dehumidifying purposes.

When you have kids and water gets onto the processor, you just dry it off. However if people are more involved with water sports, there are 3 options. 1. There is the aqua plus. This lasts for up to 100 uses and has its own coil and cord and the processor fits inside. 2. Nuclear Aqua accessory reusable. This is a plastic bag which covers both the coil and the processor and has a zip lock. Comes in a pack of 5 and can be used up to 20 times. Here's the link

<http://www.cochlear.com/wps/wcm/connect/uk/home/support/cochlear-implant-systems/accessories-/swimming-and-sport-accessories>

The CI has a 68 IP rating which means it is completely waterproof and dustproof.

Barbara said she would take it off if she went swimming. 3.

Simon: That was an option, however people still wanted to hear what was going on around them.

Marian said she would feel unsafe without hearing while swimming if she was looking after her grandchildren. How safe is the processor when using a spa pool?

Simon: When people go into a spa pool – they generally lose track of time. Also too that the steam as well as perspiring are not a good environment for the processor.

Pam showed examples of the aqua plus and also the nuclear aqua accessory. Simon suggested that the nuclear aqua is suitable for 6-7 times.

Simon: The aqua plus is a cosmetic solution for use with both the N5 and N6 and is just like a silicon wetsuit. It is waterproof and can be used in temperatures up to 40-45 degrees. However don't use it on slides.

With the N6 being wireless, there are some excellent accessories which makes for better hearing. A new invention means the processor can be attached to spectacles. This is currently going through the US FDA regulations and is hoped to be available in approx 6-8 months. This will be suitable for new people who have problems keeping their processor on.

Marian uses double-sided tape to hold her processor on as she has small ears.

Simon suggested if anyone had access to toupee tape – this could also be used.

As the CIs are publicly funded, we need to identify and lift the profile of the disability issue so that funding is generated for new people.

Rodney: Kids had no wait list and that their parents should decide to give them an implant. As there are parents who may be from the Deaf culture, the parents may not want an implant. He said this was child abuse.

Simon: It is an individual choice – and that people can't be forced to have it done. With regard to children – the brain is best stimulated at the earlier possible opportunity. To get it done within the first 5 years is huge pressure on the parents to make that decision. Babies born to Deaf parents percentage wise is very low. 80-90% of hearing impaired children are born to hearing parents and they want the best for their child. The decision is a huge one which needs to be made within the families. If a Deaf child gets to adolescence they are able to decide for themselves.

Donna had recently been to Whangarei and had someone come up and ask about her CI. This was a mother of a child who was now 8 years old. He had been implanted at the age of 2 and had been totally immersed in the Hearing House in the hope of getting speech. However after 1 year, he had to learn sign language because he only ended up receiving noise. Also recently being in touch with Kelston School, there is a very small percentage of children coming through the system who are not able to have a CI. This may be because the internal hearing mechanism has not developed or there may be growths. All avenues are explored.

Simon: There are different types of deafness and if a CI is not suitable, another option could be a Baha which is bone conducted.

Rodney noticed his hearing loss at 25 – however believes it started at 20. A lot of people don't notice they have a hearing loss until they are in their 60s and 70s – and then are put into the age related bracket.

Karel: A lot of people are counselled to see if they want a CI. If they are older, technology is harder to master and they are resistant to change.

Donna: Everyone must be given the choice. They may think they are 'coping'.

Simon: We must give everyone the information and respect the family's decisions.

Marian: I had an excellent audiologist who referred her for the CI programme.

Simon: You were very lucky.

At a recent Pindrop discussion group – consumers found it difficult to get information about where to go after hearing aids were no longer useful. Donna said this is a large problem and there is no 1 stop shop for information. Pindrop is in the process of creating a flow chart so that there are a number of avenues people can pursue to get information. They have had representation at audiologist and GP annual meetings in the hope of getting the message across.

As the population is ageing and hearing help is required more, Simon said it needs to be registered as one of the top 10 diseases to get a focus. Currently the newborn hearing screening is picking up a large number of children in need. An adult hearing screening should be something that could be implemented too.

Paul: There is a lack of funding.

Simon: Funding is an issue as there are currently approx 180 on the waiting list. However a few years ago Lyn Polwart organised a petition and as a result there was extra funding given for CIs.

Rodney: I have been 15 years on benefits because of hearing loss. There should be hearing tests for adults because it is a health and safety issue. This would ensure a baseline hearing test.

Simon: What a brilliant idea.

John knows someone who works at NZ Steel who has no hearing – however has to wear ear muffs.

Karel: The New Zealand population are committed to an 'I'm okay' attitude. This is transmitted to audiologists. We tend to keep trying harder with what hearing aids we have. There needs to be a graph which shows hearing aids and also CIs so that the public are made more aware of their use and availability.

People who start out with hearing aids and then implantable technology can benefit.  
Simon: He doesn't have anyone who has a CI come up to him to say they should have waited longer for it.

The Baha is also of help for some - and this is also dependent on hearing loss.

Karel: Obviously if it helps, the people will utilise it.

Paul: Audiologists have self interest and look after their own pocket.

Simon: The audiologist has been trained and should offer the best help possible. If I was an audiologist I would not like to have an unhappy customer.

Donna: People who are hearing impaired utilise 100% of their energy in trying to hear. The statistics show that a wait of approx 7 years shows how long before people do something about their hearing. You rely on an expert and put your hearing into their hands. I had my hearing aids in my purse for a number of years.

Raewyn: Perhaps when ladies are pregnant – they should get a hearing test as hormones can alter it.

Simon: Your GP should have on his schedule a hearing test at a certain. You generally go and see them and they always want a blood pressure and weight check. Unless you ask questions about hearing loss, it is invisible. Also too that quite regularly a doctors surgery can be quite noisy and make communication difficult.

Maxine: A number of people don't realise that they are getting deaf.

Simon: Everyone gets to the stage where they have coping strategies. And unless you tell your doctor that you are having problems, he doesn't ask.

Karel: Generally the doctor will see you in a 1-1 situation. This does not show the difficulty some people may be having.

Simon: the GP does not ask about hearing problem. Up to 30% of people with a hearing loss will benefit from a hearing aid. Remember there are lots of factors.

Rodney: A lot of the ACC benefits can be put down to being age related – including hearing loss.

Simon: ACC is making it harder to get hearing aids. They say hearing loss can be noise induced. However we are lucky in having ACC as some countries don't have this facility.

Donna: How long should rechargeable batteries last for? Also too does their efficiency drop?

Simon: Everyone gets 3. They are lithium iron and every time they charge this is regarded as a cycle. They charge up to 360 cycles before they lose capacity to charge and have a finite lifespan. To maximise their lifespan when putting them on to charge – rotate the charging position each time (suggestion clockwise). You can leave them on the charger for days on end. When they fully charge you may take them off and leave in a cool space.

Zeta: What's the lifespan.

Simon: The 1<sup>st</sup> year is 100% and then they reduce approx 20%. They should last up to 5 years. Lyn Polwart has just had one go after 6 years – and she only has 2.

Zeta: Mine last for 2 days.

Simon: The maps determine how much charge is required. Some people only get 1 full day. They are more affordable and environmentally friendly in comparison with disposable batteries.

Marian: What's the cost of a rechargeable battery.

Simon: Approx \$300

John: Should they be discharged right down after beeps.

Simon: They should not be charged every day. For children they should be fully charged so they have back-ups.

Remember to rotate on the recharging unit.

Karel: When I hear the beeps I put it on the charger straight away. All batteries are on a ratio of 80% and 20%. So when the beeps occur, this means there is 20% of battery use available and are generally 80% charged fully on the unit. Once the beeps have occurred and you keep running it right down, eventually the battery will not recharge. Everyone should get at least 1 full day and perhaps another part day.

Simon: The rechargeable batteries are Rayovac and are Swiss made. They are the leaders in rechargeable technology and can validate their use for CIs.

Karel: When the batteries are charged, there is a chip inside which picks up when the battery is full. Overcharging can limit capacity. Working in the photography industry, some photographers would full the battery, take it off the charger, and then put it back on, doing this a number of times. This limits the life span.

Simon: Each time it is on the unit this is regarded as a cycle. Different batteries have different specifications and applications. I will look into this.

John: We had an accident while the battery was on the charger. We tripped over and the battery snapped off.

Simon: Make sure the battery is disposed of at a refuse station with special facilities. With CIs, if you can stretch the battery life out for 6-7 years this is the approximate timeframe of replacement for upgrades.

Marian: The recharge unit has an unusual plug which is placed wrong for some power points.

Simon: With there being 400,000 CIs world-wide there are economies of scale. Every country in the world has different wattages. The charging unit is a uniform one size fits all.

Karel: You could use an inverter.

Pam: Can you make contact with Cochlear direct by the 0800 number.

Simon: Yes but not before 9am. As Australia is behind us timewise, staff are not at the helpline desk until 7.30 Aus time. You are able to pay in NZ \$ via credit card. The goods will be despatched and need to be signed for. Cochlear have a commitment to creating an online store available for NZ residents and this is in the pipeline. I will give you notice of when this is available. All information will be available there as well as instructional videos and promotions.

Karel: What about when repairs are needed?

Simon: In the last 12-18 months we have created a premium exchange system. If your processor is less than 5 years and has a major problem, you will get a new processor on the spot. The guarantee continues from the first processor.

Donna: I recently got a new processor as my on-off button came off. I put up with it for a few months. You need to keep an eye on how long you have had your processor because once you get past the 5 years the repair cost is \$500+.

Vince: I ended up losing my magnet recently and had to have a bandage around my head to keep me mobile until a new one arrived.

Simon: The attachment of the magnet is only to keep the coil across the internal connection. Make sure you check the magnet is tight and don't have Vince's problem.

Donna: We need to remember that there is only 2mm between both magnets. When visiting Ellen 1 year after switch on – Ellen was disturbed to find a doughnut round shape on Donna's head. As Donna was going to visit Robert Gunn Ellen made sure a lesser strength magnet was replaced.

Pam thanked Simon for his presentation and presented him with a gift of our appreciation

Donna then told members that at our next meeting we have Jay Jay from the Pindrop Foundation who will show what incentives are shown in schools to protect hearing.

The meeting closed at approx 12-15 pm.

On the way out – Donna found that the NFD autumn 2016 brochure is now out. Here is a link to download a PDF

<https://www.nfd.org.nz/our-work/hearing-matters-magazine/>

If anyone needs to contact Simon, here's his details

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