

## Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 20 February 2016 at Hearing Association, Remuera, Auckland.

Hosts: Pam and Kerry

Present: Donna, Kerry, Pam, Vince, Raewyn, Lyn, Stuart, John C, Zeta and Ged, Laurie, Gloria and John, John and Marian, Donald, Nic, Lee.

Absent: Diana Houtman (Hamilton) Maurice Hansen (Whangamata), Raewyn Ashdown, Louis and Mona, Des and Gay Brown, Di and Maxine.

Donna opened the meeting by welcoming everyone to the first meeting of 2016. Thanks to Kerry and Pam for doing morning tea.

Information recently received included 2 newsletters from the Waikato CIG. These are attached and also their poster. **(Jan and Feb attachments)**

Donna sent out a poster to all on the mailing list advertising dates with all meeting dates for 2016. This was appreciated by members who have diarised them. These have also been sent to Apollo Hearing (Albany), Dilworth Audiology, Life Unlimited (Auckland) and also the University of Auckland. Also the host and hostess list was sent to only members listed to alert them to the date they are on duty.

Speakers have been organised for the following months. They are:

**March** – Jonathan Milne in conjunction with Karel (music)

This is anticipated to be a singalong for members with keyboard accompaniment

**April** – Simon Wilson from Cochlear

Bring along all your queries

**May** – Jay Jay from Pindrop Foundation.

Jay Jay works with incentives in schools to appreciate your hearing, way to reduce hearing loss and the significance of hearing loss.

Anticipated speakers for the future include: Able Captioning, David Welch from Auckland University, Attitude TV and Hearing Dogs.

Please note the Pindrop forum this year is in September so this meeting date may not happen.

A few members had attended a Pindrop Foundation seminar in late January which included members from Tauranga, Hamilton and Whangarei and also Pindrop Board members. Hearing therapists also attended.

Donna had been having problems with her processor turning on. The orange light showed that the battery was connected properly to the processor. However the green light to say the processor was switching on okay was delayed. She was getting to the stage where she was trying to switch on a number of times. This has been a problem she has had for the last couple of months, but she had soldiered on. She had found that the on-off switch had come off onto her finger and underneath was a plastic button. She had put the silver switch back on – however this was not

connecting correctly. After having the silver switch come off for a second time, she decided it was time to do something about it. Contacting Silvia at the Auckland University, she thought she was going to get a loaner. New information had been presented at a meeting previously by Lee to say that if your processor is under 5 years (and guaranteed), it would be replaced on the spot. This is what happened in Donna's case. However as her processor was 4 years old – the new processor is only guaranteed for 1 year (totalling the 5 years of the original processor guarantee). It is important that if anyone has a problem with their processor they get it sorted. Silvia said a person had been having problems with theirs for a couple of months and when she organised to do something about it, it had gone past the 5 year guarantee and she had to pay \$500 so it could be sent away for repair.

Discussion transferred to insurance companies and whether the processor needed to be itemised separately. Ged said his company would insure it for 5 years – however after this time had to go private. John C says he has his insurance with AMP and has never had a problem. (Some insurance companies say to list it separately and others say it is already included in contents – you may need to check).

Over the Christmas / New Year period, Vince lost his magnet. His wife contacted Cochlear via the 0800 number (0800 444 819) which is answered in Australia. This was on the Wednesday. Unfortunately it got held up in Sydney on the Thursday. He received his magnet finally on the following Tuesday. (Remember Christmas was on Friday and Monday was a Public Holiday). This was a bit distressing as it was thought he would be offline because the magnet was required to get sound. Apparently the magnet is only required to fix the coil to the head. So Vince was able to put a bandage around his head and still hear until such time as he received his new magnet. Friends thought Vince had had another health issue and wanted to know what the problem was. (Members might like to check their magnet on a regular basis to see if it is loose and adjust accordingly).

Silvia from Auckland University said if people required spare parts, etc over the holiday period, to just contact the University either by telephone or email. The phone gives you a mobile number and one person from the university has this with them over the holiday time. One person over this time had made contact.

Pam had contacted the Auckland University in early December because her adaptor cable was separating from the plug. She is still waiting for a new one. Also she found an ear hook for the Aqua plug had become brittle and she had needed a new one. Donna said to remember to pull the hook away sideways rather than down. As the plastic goes all the way around they are easy to break.

While visiting the Auckland University, Donna had picked up a newsletter from the NZ Tinnitus and Hyperacusis Network. This is headed in NZ by Grant Searchfield and is sent out a number of times a year. Because the tinnitus field is such a small one, information is gleaned and shared from around the world. Attached is the 2015-2016 summer issue for your perusal. These newsletters are intermittent and authors have other day jobs. There is the ability to sign up with *PLEASE ADD* or remove *REMOVE*

FROM MAILING LIST. The email address to do so is: [tinnitus@auckland.ac.nz](mailto:tinnitus@auckland.ac.nz)  
(Summer 2015-2016 edition)

Donna thanked Pam for advising her of My Tiny Reminder which is a wide mesh band with Velcro with a small alarm inside. This is useful for waking up on time. She had found it invaluable and made her independent.

With this in mind, Laurie was asked to read an experience he had sent to Donna

*I wanted to relate an experience I have just had recently so as follows:*

*I was asked by a friend to come and cruise on his launch for 7 days in the Marlborough Sounds.*

*The worry for me was getting there – through the airport and all the drama involved with self check-in etc. Being deaf I had lost all my confidence and my wife has always tended to do these things for me. So this was scary stuff.*

*On my own – first thing was glasses on and up to the machine. Well, I worked my way through the screen and paused for a few seconds. Next thing the machine asks "Are you still there Lawrence?"*

*Well only my mother called me that! I am usually Laurie. I pressed "yes" and carried on and then to my dismay inadvertently pressed "yes" for "Are you carrying a firearm?" Yek – quickly I pressed "No"*

*Eventually I got there and thought "wow I did it!"*

*Then into the departure area and within a few minutes two armed police officers arrived and appeared to be looking at me! Crikey I thought – I have done it this time!*

*Then two more armed officers arrived – four of them – bit much for me. I was going to go quietly anyway!*

*A few minutes passed and they disappeared behind a closed area and came back with an islander chap in tow. It wasn't me they wanted. So, we all had a laugh at Laurie's expense. It made a great story on the launch over a few drinks, so I just wanted to share this with you all.*

*Bottom line – having been deaf for so long and having to rely on my wife so heavily has taken its toll but this experience has taught me "I can do it!"*

*I am slowly getting my confidence back.*

*Watch this space.*

*So grateful to the Hearing Fraternity. It has been a great journey. We love my CI!*

Laurie's experience makes us aware how much we rely on others. However when we have done it once, we are pre-prepared and know we are able to do it again. Isn't it great that the CI gives us independence.

With this in mind, late last year there was the storm where we had 1300 lightning strikes in Auckland (between midnight and 6am). Donna had recently had her smoke alarm installed and when she was woken at 2.45am due to lightning she thought it was her alarm going off. However when she found her bed did not vibrate, was pleased to not have a fire. Later that morning she checked with her son and his girlfriend to see if they had been woken up, and they said no. It is amazing that she thought she was protecting herself and being independent and could have ended up saving her family as well.

Donna had recently been to Whangarei and while waiting to be served in a shop had a customer approach her. Her son had been implanted when he was 2 when it was found he was deaf. They were told to not teach sign and exclusively use sound. However after a year of therapy at the Hearing House, he was unable to distinguish different tones and frequencies and all he seemed to be getting was noise. At this stage he had to learn sign. The lady behind the counter was also interested in CIs and said her brother may be have to get one. Donna left her contact information.

We must all appreciate the sound-voice recognition we receive when we get a CI and not judge how others are getting on. We are all individuals and everyone adapts at their own pace. This is the reason why when people want to know how well we are going, we need to let them know that this is a life-long learning experience. Even years on we may hear new things.

John L had recently purchased the alternative medical bracelet. He had purchased a silicon bracelet for \$14 (includes postage) and found they also do 'dog tags' in a necklace form for \$8 + postage (tags available in metallic red, blue, green and black. Chain approx 76cm long – however different length can be requested). He had these at our meeting for people to view. Information you can include are your name, hospital number and allergies, etc and perhaps an emergency name and number. <http://www.pettagsnewzealand.co.nz/wristbandid.htm>. If people are interested in the dog tag they need to go to the 'contact us' section. He had ordered one day and received them the next. All emergency staff are aware of their use. Also as they are a one-off cost, you can replace them when you want. The Medical Alert bracelet is approx \$50 per year.

There are currently approximately 60 on the total email list with 10 being from other clubs and the South Island.

Latest news items are as follows

Churches too loud and turning parishioners away

<http://www.stuff.co.nz/national/75103953/churches-crank-up-the-volume-but-the-earsplitting-worship-is-damaging>

Noise pollution affecting health

<http://www.mindfood.com/article/how-noise-pollution-is-affecting-your-health/>

This item was put on the Pindrop website.

Nic said the recent seminar was held in conjunction with the Health Commission. The plan was for the strategy to move forward in the next 2 years.

Last week Karel, Lyn and Josie (Tauranga) had been to Wellington and talked to Annette King, Labour's health spokesperson.

Karel got up to speak about how they were received. They had all sent information to Annette before and she was well briefed and asked pertinent questions. She wanted to know what it was like to have the surgery and what it was like to wear a CI. The technical problems involved are related to the funding. The limited funding

does not equate to the need. She is sympathetic to the cause on behalf of the Government.

Marian queried a news release about the funding reduction required by the DHBs because of budget blow-outs.

Lee said the funding for CIs comes from the disability area and we are not affected by the above.

John C introduced Neil. John C said he had travelled the world and we don't realise how lucky we are in NZ with regard to our emergency services. His quote 'we never plan an accident'.

Neil Lilley was our speaker from the 111 St John Ambulance Centre.

There are 3 sectors which cover New Zealand. Auckland, Christchurch and Wellington and they are all linked electronically. When you call 111 Ambulance the call may be answered by either centre. The main information needed by the operator is your address, suburb, city and telephone number.

The international Medical Priority Despatch is the same triage used worldwide. Computers have been upgraded recently to keep up with change.

When people ring up, there are different screens of information available dependent on information supplied regarding the patient.

Colours are given to each priority. Purple = urgent. Red = stroke, chest pain. Orange = not as urgent. Grey and green = are low priority where someone has diarrhoea or vomiting.

Ambulances for purple are expected to arrive within 8 minutes. Nurses and paramedics are at the centre. If your priority is green, they will ring back within 15 minutes and ascertain whether a GP/nurse/doctor will visit.

All 111 calls will not necessarily need an ambulance. 4WDs and motorbikes are also utilised as ambulances.

When on a call to 111, the operator may still be talking to you and there is no delay in response. At the same time they are inputting information, it is being relayed to the ambulance which is attending as they have computers on board. If someone has sent information via the 111TXT service, this is also relayed.

Donna asked if we could ring up on 111 and relay information and then change to 111TXT afterwards (if registered).

Yes that is no problem as sometimes when they have foreign people ring up – they contact an interpreter and there is a 3 way conversation. This does not slow the process down.

They always respond to a 111 Ambulance call.

Within the system of ICAP, Spark allows information to be supplied which may show addresses. However if you have a prepay, there is none of this information. However if using a mobile phone they are able to use GPS and may be able to locate you.

Laurie asked if we call – should we stay put.

Yes – because sometimes advice is given over the phone which may help.

John L – Do you get the address off the phone company.

Yes if it is a landline but mobile phones are a bit more difficult and sometimes the signal may be intermittent.

Donna said there could be a problem if people are in a body corporate as they do not want to have a key available.

St John in some instances has the access codes and are able to enter property.

John C said some apartments could be a problem to get into.

The St John in that instance may have a point of contact (caretaker).

John C said this particular instance was when a woman had fallen out of her bed and had used her personal alarm. The St John was unable to enter because of the body corporate policy of not allowing codes out or no key was available.

When people have a medical alarm, information is supplied and a contact person / phone number is available.

When a group had visited the Northern Police Communications Centre, Donna had suggested they use a logo to identify a property or car where people were deaf. This could be the logo off the 111TXT brochure which shows 111 and 3 emergency vehicles below. If these were sent out to people when registering for 111TXT or made available through various hearing outlets, it is a visual reminder of extra care needed.

Raewyn said she had been disturbed to find the next day that police had been walking around her property during the night and thought the idea of a sticker (as above) would have made the police aware that she would not answer a knock.

In Britain they have a fridge magnet which alert emergency staff to hearing impaired householders. (Not too good if you have lots of fridge magnets).

Donna said the advertisements about the 111 service last year were a bit off-putting. However they get a huge amount of nuisance calls which have to be dealt with. She felt that if hearing impaired people required the service, they were ringing because they needed help.

Some people don't understand that if they run out of medication over the weekend, the 111 service is not what is required.

John C said we need to make sure we are clear about what service we require. When ringing through the 111 there is the fire, police and ambulance.

John L said if you are ringing you may need to tell them you are deaf and they may need to break in.

Donna said a niece had required the service and had a delayed answer time. It was suggested that information be repeated if you can't hear on the telephone.

Sometimes in the 111 services there are multiple calls at one time via mobile telephones about motorway accidents. These need to be cleared quickly so that other emergencies can take priority.

Lee queried how they are able to recognise different languages. Normally callers are able to relay in English what language they are using. He was interested in how the St John is funding. Some of it comes from the Ministry of Health, DHBs, ACC, and through charges. Some are contracts which are only valid for 1 year.

Donna said it was important to become a member of St John. \$45 single, \$60 couple, \$75 3+ at same address. This is an annual fee.

If St John is called and you don't have a membership the charge is \$88. ambulance. John L said he had called the ambulance and it had taken 20 minutes to arrive. Their recommended city response time is 8 minutes, rural 12 minutes and others 20 minutes.

One of Donna's family had needed an ambulance and one wasn't available. So the Fire Brigade was sent as they have an onboard defibrillator. They were able to help until such time as an ambulance was available.

John S said the fire brigade had at times been called out and people were expecting ambulances to turn up. When the fire brigade turned up they were told to 'bugger off'.

The fire service is able to help in all purple calls. They have life support and defibrillators.

Marian asked when a rescue helicopter is called.

When a helicopter is required, coordination between various services are needed and St John manages this. These can include SAR, Coastguard, police. Some of these instances require a helicopter to winch people out.

John C asked if there are many abusive calls.

Neil said he had worked in Britain and found they used to have a number. However since moving to NZ he said they hardly have any.

Ged asked if they needed their drivers needed special training.

To drive under lights and sirens – there are certain courses.

Donna said that perhaps they needed a defensive driving course.

Stuart thanked Neil for his informative talk and presented him with a token of our appreciation.

John C asked whether they had networks related to the traffic cameras.

St John has just been allowed to access this if required.

John C said the camera centre located at Smales Farm is perhaps a worthwhile visit. He said they are able to view visually and locate the correct areas where people are.

Neil said they have access to rural maps and if notified via a mobile phone can ping towers and get GPS locations.

There has been a recent update to the databases of Fire, Ambulance and Police and information can be sent electronically to all services.

Neil issued an invitation for a small group to visit the centre in Mt Wellington. This is a wonderful opportunity and Donna will organise and let members know.

The meeting concluded at approx 11.45 and members conversed afterwards.

### **Attachments:**

Waikato CICG – Jan newsletter

Waikato CICG - Feb newsletter

Sounding Board – NZ Tinnitus and Hyperacusis Network (summer 2015-2016)