

Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 18 June at Hearing Auckland (Hearing Association), 8 Vincent Ave, Remuera, Auckland.

Host / ess: Stuart and Raewyn

Attending: Donna, Kerry, Vince, Maxine, Pam, Barbara and Paul, Karel, Hanna.

Apologies: Zeta and Ged, Carolyn, Michael Lee, Anita and Frank, Lyn, Di, Laurie, Maurice and Pat Hansen, Des and Gay Brown, Rod and Helen McAlpine, Rodney.

Many thanks to Stuart and Raewyn for supplying morning tea.

Please let me know if your email changes. It is disappointing to have emails bounce back because people have not let me know.

An update from Kerry regarding the financial situation. We donated \$50 (which was donated at our April meeting) to New Zealand Captioning Working Group for help to get subtitles for the Rio Olympics. Currently we have funds of approx \$190.

Donna has been received texts and emails from NZ Police for the 111TXT service. When checking with other members, no one else is having this problem. She had registered in October last year. In January she had 4 emails and texts over 2 days. In June she had 4 emails and texts over 2 days once again. Karel suggested it may be spam. These messages are saying that her password has been successfully reset. She has emailed a contact at the Northern Communications Centre – however has not had a reply yet.

(Donna has since gone onto the website and had to utilise the most recent text message and altered her password successfully).

Raewyn had registered for 111TXT approx 8 years ago and had never had any problems with this service.

Karel suggested it may be an idea to get net safe to talk to our group. He had had a recent email saying a subscription had expired and he had had to unsubscribe. His credit card details had been accessed. When some people go 'fishing' for information online, they only need to put in

a few expiry dates and they may be successful. He had had to cancel his cards because of this problem.

Donna: When you get emails from the NZ Police and banks, you think everything is okay.

Recently going to Christchurch Donna was surprised to see that a Countdown had a pharmacy inside. Also was a clinic for Bay Audiology. Apparently this is 'normal' in Australia. Some members said this was a great idea because some people have transport issues. Also a good way to say you are going to the supermarket without having the stigma of having a hearing test.

Staying at a B&B in Wellington Donna was pleasantly surprised to talk to the owner who had a friend who had 2 hearing aids. She had come in looking a little bit troubled, and said she would tell her friend what the matter was later. Apparently she had heard rain for the first time on the roof of her house and car. Her hearing aids are Bluetooth enabled, and can enjoy music at the same time as hearing the world around her also. A newspaper clipping picked up a few days later in the Christchurch Mail showed that hearing aids are becoming easier to use with new technology, making them user-friendly devices. Using a wireless connection, hearing aids can pair with an owners' Android or Apple device, giving them the option to discreetly and easily change settings through the phone's touchscreen. "Hearing aids are already pretty good at being automatic and adapting themselves to different environments, but this makes any user adjustments very easy". Because we are in the world of CIs, we probably haven't noticed that technology in the hearing aid world is moving on as well.

Karel remembered a deaf grandmother who used an ear trumpet to get some semblance of sound.

Watching TV

Barbara with her hearing aids has a cord around her neck and is able to adjust the volume on her TV with her phone. This means there is no cabling to trip over in the room.

Donna said when all TVs needed to be digital, she had been to Noel Leeming and Harvey Norman. Apparently if anyone was deaf – they only wanted to know how high the volume went. Only a few representatives knew about subtitles. And with the latest technology, more programmes are subtitled.

Karel said TVs are best if you have a speaker at the bottom. Extra speakers are available.

Donna: Also the situation your TV is in can change how it sounds. She had been in the room at the B&B and the TV was to her front left however she felt the sound was coming directly from her right. If you have a TV in the kitchen there is no furnishings or carpet to reduce tinny type sound.

Raewyn: N6: I have a mini mic but still seem to have a tinny sound. I only have 2 programmes.

Karel: You may need to contact the university to get more programmes and take your mini mic for the programming to marry together.

Hanna: Does anyone do home assessments of people's requirements.

Donna: There is the hope in the future that there may be a co-ordinator or one-stop shop where everyone is sent to get all information.

Obviously this position needs to be funded. Pindrop can see this is a huge need, however this will take time. All information needs to be individualised.

Karel: Everyone in the system needs to have information given in stages. We are unable to absorb all the information at one time. Also as people become better at using the equipment, they have different questions. Some people are not really gadget aware.

Donna: Cochlear has created the welcome package. Every month new recipients are sent a video for their first year to get them up to speed with their new gadgets.

Someone suggested a while ago to look on u-tube. I found watching a 20 second video that I learnt 3 things – this was one of them. *Taking off her processor, she is using disposable batteries. Remove cover and use the coil magnet to uplift batteries – these jump up and there is no need to lift fingernail underneath).*

Paul: perhaps we need to have mobile audiologists.

Karel: that's an excellent idea for people who have mobility issues. However we need to remember that an audiologist has a financial incentive. We need someone who is independent. When I was a minister and people learnt I had a hearing problem, they would line up and there would be a queue of people to ask questions. Sometimes the solution was to take the tag of the disposable batteries. Or that people hadn't turned their hearing aids on.

Maxine: *Used to be a hearing therapist.* Unfortunately the hearing industry is extremely fragmented. Within the Hearing Therapy service, we are funded by the Ministry of Health. However we are restricted to what we can and cannot do.

Another newspaper clipping from Kapiti News showed an 18 year old student who had studied NZSL (NZ Sign Language) at Auckland University of Technology and had won the Media Award. She has embraced Sign Language over the last 3 years and has taken to social media to advocate greater emphasis on the language form. She had emailed 218 high schools that achievement standards are begin written for NZSL at NCEA levels and the Ministry of Education hopes these standards will be available by 2017. She had created a film and it was one of the 20 wining films out of 156 entries in the 'Outlook for Someday' film competition and won the Rockstock Media Empowerment Award.

"If more people learned NZSL our society would be more inclusive and have fewer communication barriers in the workplace, school or neighbourhood."

Coming back to our topic of sounds, have people noticed that the sirens of police, ambulance and fire engines are different. It is great to recognise these and know which emergency vehicle is on its way.

Our meeting centred around our best and worst sounds with either hearing aids (HA) or CIs.

Donna:

HA: best – when I first got digital hearing aids everything was CD quality. However after a while it w as not so great. Didn't realise it wasn't the aids, it was me.

HA: worst: walking into a room where approx 20 people were talking. Feeling like the top of my head was going to explode because of the noise. Putting hands on head.

CI: best – Sole Mio concert where you could hear a pin drop. Then because piano music and then awesome singing. Did not know who they were previously – had won some tickets.

CI: worst: Just after switch on – going to the toilet and flushing. Sounded like shattering glass and also felt like it hurt to hear this sound as I had not heard it for a long time. (especially high pitched sounds)

Lyn:

Worst: background sound when people are talking e.g. Masterchef.

Best: sound of happy children at play

Sound I miss the most: the rain and thunder on a stormy night when I am snug and warm in bed.

Stuart:

I lost my hearing through an accident and for 20 years I had no hearing.
Worst: a recorded interview with a correspondent with a low and perhaps distorted voice. Sometimes they have an accent and this is on Radio NZ. I can hear the NZ radio journalist clearly, but the recording is unintelligible.

Best: Tuis calling, which I could not hear even with hearing aids.

Raewyn

HA: worst – harshness of noise – everything seemed to be noise.

Standing at traffic lights waiting to cross, feeling the vibrations of cars.

CI: not harshness

Best: Kids at preschool across the road from my home, birds singing, talking to friends on the phone and understanding 90%.

Hard: Flushing toilet, kettles boiling. Clock ticking – when tired.

Pam:

Worst: Hand driers (especially the ones where yours hands need to go up and down), screaming kids, jug boiling, music, shopping malls, coffee machines.

Good: tuis in bush. Pam has found that the tuis in the bush sound different to the tuis by her house.

Visit Tiritiri Matangi and guides can alert you to the sounds and where and what the birds are.

Apparently tuis can learn different sounds.

Barbara:

Worst: her previous hearing aids – she could hear the bus coming from a long way away. Doesn't hear the sound of the buzzer on the stove.

She puts timer on her phone.

Good: just to hear. However likes to know what sounds are.

Hanna:

Worst: high pitched sounds, keys jangling in your hand, plastic bags, people changing pages in the newspaper.

Best: Birds, waves, hearing someone talk.

When she can't hear well, she needs to concentrate and this increases stress.

Karel:

CI: worst: at a foodbank helping out, having teenagers rustling plastic bags and the sound making him feel physically ill.

Best: walk on the beach and hearing the waves falling over onto the sand.

HA: worst: when in photography occupation was working in my workshop. Hearing and psst sound which was intermittent. Trying to locate the sound by climbing on ladders and crawling around the floor – ended up wasting a whole morning. His wife was not home and ended up phoning her. She was able to locate the noise. He had had some frames and paperwork on his desk. Every time he knocked against them, this is when the sound came. He had a small vacuum cleaner on the desk and this was where the sound was coming from.

Paul

Worst: music and people trying to talk over the top

Vince

Vince drove trucks for 20 years which resulted in noise induced hearing in his left ear. Driving trucks for 10+ hours it took a while for the hearing to come back when the truck stopped.

Hearing aids were useless. CI music took time.

Kerry

HA: The fridge seems to roar. A visit to Royal Oak, the traffic noise was incredible. It's a struggle to hear and its hard work. Annoying making a journey by train on your own when you can't hear announcements.

Barbara: When I am placed onto an aeroplane, if you tell them you have hearing aids, they will put you in front of the wings and engines. When I have sat behind the engines, I can't hear anything.

Donna: My husband recently booked me on Jetstar and put me down as being deaf. The only thing this helped with was that on seat request, they made sure I was on the left of the plane as my processor is on the right. As the original booking was unable to be changed as she didn't need extra help, she knew that the information would probably be on the flight manifest for the attendants. However she did not receive any extra help. Why is this service offered, if staff training is inadequate. A survey has been sent via email and she is going to offer suggestions. Apparently too if people need help, they are generally located at the

front of the plane. This is so that the flight attendants can offer assistance to those that have the greater need.

Raewyn: When I went to Perth recently to visit my daughter on Air NZ, she had requested personal assistance. They small group of disabled people were whizzed through everything and were put on the plane first. However on arrival, were the last off the plane. They were escorted through the terminal to the bag pick-up point also. On her return flight, this service had not been requested.

Stuart: on a flight was asked in a loud voice "Everything all right Mr Tunncliffe'.

Some of these services and help which is available, you need to ask for them.

Maxine:

CI: good: sons graduation. She requested help as to where the best seating was and was told right at the front. Having previously been to graduations at the back of the hall, and not ideal situations, she had the best experience.

Pleasant: early CI – working in the office and hearing other staff taking bookings over the phone. Catching snippets of these conversations. When they are off the phone, she was able to repeat and they accused her of eavesdropping. *Sometimes this is when the best information is imparted.*

Favourite: Autumn leaves crunching underfoot. Checking out piles of leaves and making sure they are not wet. They need to be dry to have the best effect and crunchiness.

Knowledge: That I can pick up the phone have a conversation. Previous to CI, had to have people only a foot in front of my face to get information. Feeling part of a group and able to contribute. After switch with teenage son and nephew being able to hear what was being said behind her back and able to repeat it back to them.

Before implant having a obscene phone call. As she was unable to hear she had the caller repeat what they said 4 times before she understood what was being said. She said at least he was persistent. But was able to give him an earful before placing the receiver down.

Pindrop had held an exhibition of CI photographs the previous week. Donna had booklets for people who had been unable to attend. A

number of recipients had been photographed in various locations with personal insights into their journeys. Pam, Maxine and Stuart had attended and said the short video presentation was incredible. It has only been shown once as the copyright is being secured to be able to show it worldwide. This has a huge impact and has stories from all people photographed. Maxine was interested to note that one of the CI recipients had 9 members of their family with dramatic hearing loss. Pam had since looked up Josie's online facebook page and read about her journey. Josie is from Tauranga. Please note: Woman's Day this week has her story in conjunction with Aynsley.

Next meeting - July

A guest speaker has been organised and is Danielle Beston from Hearing Dogs

The meeting closed just after 12noon.