

## Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 19 September 2015 at Hearing Association,  
Remuera, Auckland.

Hosts: Maxine and Rodney.

Present: Donna, Donald, Zeta and Ged, Marian and John, Des and Gay, Pam, Raewyn Ashdown, Nic, Anita and Frank, John C, Laurie, Lee, Stuart, Karel, Gloria and John.

Absent: Diana, Kerry, Di, Louis, Lyn, Lysie (Tauranga co-ordinator)

Donna opened the meeting by welcoming everyone. Recent newspaper clippings x3, (attached as jpgs). 8 people signed up for next 111TXT visit – no more visits this year. As minutes had gone out about the last visit – people to put their thinking caps on for more questions. One Donna did not ask was how many have signed up for this service.

John L had bought the book along **Katherine Bouton - Shouting won't help: why I – and 50 million other Americans – can't hear you** which is available from Auckland Library. This is a book mentioned on the list for new members. John S had also recommended that partners of hearing-impaired people should read as it makes it easier to understand the problems they faced daily.

Fair Go on 19-08 had a story about a 93 year old lady who had a St John medic alarm. She had pushed it and had not had anyone attend. The problem was that she was part of gated community and the body corporate did not to put a lockbox at the lobby for emergency services to gain access. The woman moved out.

Donna had had a relative visit her father and had needed to contact the ambulance. There were no emergency family numbers by the landline and this needs to be addressed. Also if people have a cellphone – make sure you have an **ICE (In Case of Emergency)** number in their list of contacts. This is a number that police, ambulance, etc, can contact a family member to advise what has happened.

The Hearing Association has been secured for meetings until the end of the year. As sometimes space is at a premium, we have to accept this for now. The Hearing House will possibly have room for us next year – and Donna will need to visit to see where and how. We are thankful to both facilities for their generosity allowing us to utilise their room as they don't charge us.

Donna wears glasses and wonders how everyone gets on with the grating noise generated by spectacles and processor rubbing against each other. She originally had a velvet stick-on on her spectacles stem and this reduced the noise. However she is thinking about getting new glasses and this is a problem with the thickness of the stems as it may stick her ear out more than it does already. Raewyn said she has put a corn pad on hers. Lee said that perhaps that was not a good idea as the corn pad has chemicals on it to make them drop off. Hopefully her ear won't. Karel said it doesn't worry him with his regular glasses, however when he uses glasses for

using the computer, he has put a rubber band around the stem. Lee even suggested perhaps sticking plaster.

People who had sent letters to MPs regarding cochlear implants had received replies. Donna had received both an email and a letter from Nicky Wagner (which is included as a jpg). This is a recent press release. She was pleasantly surprised that she sent emails out at 8.30am and within 15 minutes had a person reply from Annette King thanking her for her personal story.

Friday 18<sup>th</sup> September was loud shirt day. Donna visited her local Pak n Save and was disturbed to see Canteen out collecting.

A couple more recent newspaper clippings with links:

Hidden hearing loss

[http://m.nzherald.co.nz/lifestyle/news/article.cfm?c\\_id=6&objectid=11506213](http://m.nzherald.co.nz/lifestyle/news/article.cfm?c_id=6&objectid=11506213)

Deaf trying to get subtitles for RWC

[http://m.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=11506306](http://m.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11506306)

Man with hearing dog unable to find accommodation because of dog

[http://m.nzherald.co.nz/lifestyle/news/article.cfm?c\\_id=6&objectid=11509048](http://m.nzherald.co.nz/lifestyle/news/article.cfm?c_id=6&objectid=11509048)

Pam said she is part of a gated community and dogs are not allowed. If you want an assistive dog you may need to go direct to managers of the facility to see if you can have an exemption. John C said he had recently visited the Guide Dog facility. And as they are helping dogs they are okay in a residential area. They are thoroughly trained and are very compliant. They are only in service for approx 10 years. John S had borrowed an assistive dog in-training for a day as he was moving around a lot and his manager had grave doubts. However when moving around telephone exchanges, there were no problems. Maxine said assistive dogs go through rigorous testing and regulations.

Hopefully everyone has filled out their thoughts about the Pindrop Foundations forum for 2016. We need to give them ideas as to what we want from it this year. People need to put their thinking caps on and give constructive ideas.

Please don't forget about the facebook Pindrop website. You do not have to be on facebook to access this information, and there is lots of interesting stuff. Here is the link:

<https://www.facebook.com/pindrop.org>

Information on this website is updated regularly and some of the newspaper items mentioned above are here also.

Nic got up and said that with the NCIT – they are funded by Government and Pindrop is a subsidiary and listed on the charitable trust register. There had been a lot of recent discussion on facebook. Enclosed is a response to questions posted.

Lee got up and said originally the ADHB was given CI funding and 10 years ago NCIT was created to get the money working effectively. Pindrop works in tandem and both have the same directors. Since taking over the amount of funding has

quadrupled meaning more CIs. Lee telephones MPs in Wellington every month to keep CIs in their thoughts. With the help of Pindrop – individual voices are able to be heard through the funding they receive.

With the above mention about sending personal stories to MPs, we still need people to send the information. Also if partners want to send information, this would be great to have a different perspective on how hearing loss affects their lifestyle.

There is to be a presentation at the Health Select Committee later this year so we need to be in their thoughts.

With Nic from Pindrop, she is helping us gain knowledge and is able to help with funding research and advocacy.

Donna said the last letter-writing we had sent to MPs a few years ago had resulted in her being phoned by Tony Ryall's press secretary to ask if it was okay to utilise quotes in her letter. Donna said that was okay – however when the press release came out it was condensed and this information was left out.

As a result of the above – next month will be about members. Approximately 3 years ago when meetings were held – members talked about their personal hearing loss. As there has been a huge increase in members it was decided that an A4 page about their hearing loss with a 5 minute time frame to make us aware of other's journeys.

Karel was introduced as our speaker on music listening. From an early age living in a 2 storey house with his grandfather above who was a conductor of an orchestra, Karel was involved in music. He learnt music and Dutch at the same time. He played the pipe organ in his late teens and later the piano. However he ended up getting cancer in his hands so could not play the piano any more. As a teacher of maths and science with music as a sideline, it was also important in his role as a minister and counselling. Hearing loss started in the mid 1980s and he said people started mumbling. In 1980 he couldn't hear clients and members of the parish. Photography became his next career.

Before his implant, music disappeared. The whole song could play but pieces were missing and they were retained in his memory. When he could hear no music, he expected to be able to hear some after implantation.

4 years ago he had his implant. He found playing scales on the piano did not sound the same. He had to train himself to hear the same as before and it is not his hearing that needs to be trained – it is the brain.

He found his congregation sounded like frogs when they sang and couldn't recognise tunes. He has trained himself by wearing music headphones while walking and playing the same music over and over again. At church he sang what he thought was in tune – however his wife would elbow him when he wasn't. 11 months after switch-on came Christmas. All carols still sounded like frogs and nonsense. However 1 week later at New Year's he found that music made sense – sound was different and the tunes became okay. He found that hearing music could change in huge leaps then plateau.

He had tried using a hearing aid with the processor and found it dominated it. The hearing aid was adjusted and this helped.

He attended philharmonic music and found it enjoyable. He thought he may not be able to hear it successfully.

If music was enjoyable, listening to new music was enjoyable, singing was enjoyable – then DO IT.

Karel then played 3 different tunes and saw members tapping their toes. The first had a good beat but was hard to hear words. The 2<sup>nd</sup> was Sole mio which is very popular and some members also mouthed the words along with 'it's now or never'. The last piece was classical Beethovens 5<sup>th</sup> Symphony.

Marian who has had switch on only weeks ago said she found people to be negative about being able to hear music well. People had said the main focus of CIs was effective speech. As she has a grand-daughter involved heavily in music and studying at Auckland University this played a huge role in her life. She said she has found music enjoyable to listen to and is now listening to it every day. The first time she heard it she said it was very emotional.

John L said he had heard on the news about someone who had had an injury to their head. As a result they could not speak answers but could sing answers. Their speech memory had gone.

Pam had bought tickets to a Neil Diamond concert who she really loves and wanted to experience once again. She had managed to secure tickets at the front and is to be held at the Vector Arena.

Others who have attended concerts have found enclosed environments have made it hard to hear. By altering the sensitivity and increasing the volume – it may help. However there may be an increase in surrounding noise.

Donna found that by taking earphones to concerts, she was prepared if there were any problems as they reduced the sound by 30dB. She made sure she alerted staff in case they were videotaping. She had been to a concert involving members of Split Enz and part of the symphony orchestra. She had asked where the best seating (hearing) position would be and was told to be half way back and in the middle. It had distorted after the first 6-7 songs. The orchestra got into playing music and as they warmed up, the sound engineer had no control. As it was the first night – the feedback was appreciated and modifications were made.

John C said we need to make sure we seat ourselves correctly. Obviously if your implant is on the right hand side – you sit on the left so everyone is beside you. Also too to make sure you sit in the middle. If you sit on either side, the music may distort. As Karel had the player over to one side – he said meant people directly behind it would have had the best listening.

Karel also said it was best not to sit near the front being too close to the speakers. Also too that some distortion may come direct from the microphone.

Karel was presented with a thank you gift from Laurie.

Discussion continued until after 12noon.