

Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 18 April 2015 at Hearing House, Greenlane, Auckland

Present: Raewyn Moffitt, Stuart, Kerry, Vince, Donna, Zeta and Jed, Maxine, Louis and Mona, Donald, Marian and John Stevenson, Nic, Di, Apii, John, Lee, Laurie.

Absent: Karel, Lyn, Raewyn Ashdown, Anita and Frank, Pam, Diana and Fred Houtman, Rosie, Virginia, Michael Lee.

Donna opened the meeting by welcoming everyone.

Marian and John were attending the meeting for the first time. Marian has been a nurse all her life and because of hearing loss has had to give up. She is about to be assessed by the University of Auckland for eligibility. She has moved from north of Auckland to south Auckland and her support network has been left behind. As there is a group of 4-5 near her location, we will support her.

As the Hearing House is under renovation, alternate venues are required. The May meeting date is under review – however there may be 2-3 months needed to be elsewhere. Nic suggested contacting the University of Auckland and if required will pursue this. Maxine said to contact the Hearing Association. Appropriately enough Donna is going to a meeting on Tuesday and will make enquiries. They are in St Vincent Avenue, Remuera and there is off-street parking.

Donna had recently become aware of a disposable battery box. By placing your used batteries and taking it to Bay Audiology – you can receive 1 new pack of 6 batteries free. These were given out at the meeting. Also too that for every 1kg of batteries sent back \$1 is given to both the Northern and Southern CI trusts. If you order online, they send you an envelope and you can post the box back and get 2 boxes of batteries free. Donna had recently tried using Panasonic batteries and was disappointed as the batteries only lasted 1-2 days. Her Power One batteries supplied in the black bag from Cochlear lasted 4-5 days. She had ordered online (\$40 for 10 – free postage) and received Rayovac batteries and these are lasting longer. Di said she got hers from the Auckland University and they were called Zenipower. Cost \$45 for 10. Lee was at the meeting and suggested that it could be worthwhile to look into buying in bulk.

Returning our attention to the Pindrop Foundation's Forum, we gave Nic and Lee a round of applause. Everyone appreciated the effort which went into this. Donna said she enjoyed the subtitles and sometimes referred to them.

Members were asked to comment on various workshops they attended.

Support for partners - Dr David Welch was attended by Maxine. Obviously partners take the brunt of supporting their hearing impaired partner and what help they may need.

Maximising CI technology - Stacey Butler, Cochlear Ltd. A number of members attended this and Stacey suggested that even though we think we hear well, we still need to practice listening skills. One suggestion was <http://angelsound.tigerspeech.com/> Even though it was more of a children's listening programme, there is the ability to listen to music. She suggested checking you tube for how-to videos if you have any queries about utilising your CI equipment and obviously there is support via the Cochlear website.

Introduction to Consumer Advocacy - Dr Chris Welsh and Sue Ellis was attended by John. He didn't think he learnt anything from it. However Nic said this particular workshop was more for CI people to make direct personal contact with government and DHBs officials to the benefits.

Fire Service Safety - Phil Faidley was attended by Di. She said he was an excellent speaker – however as we had already had him as a speaker at our meeting recently, she didn't learn anything new.

CI eligibility – Caroline Selvaratnam was attended by Stuart, Vince and Donald. Mainly directed to professionals but they found it quite interesting.

A consumer perspective – Karel Lorier was attended by Raewyn and Donna. Karel had had to change to different careers a number of times to support his family. He found his wages fluctuated depending on how good his hearing was. It was great that our audience was varied and included Jim Patrick, professionals and Ministry of Health representatives.

Lee said it was great to have Pat Tuohy, Chief Advisor, Ministry of Health attend. Generally these people are dealing with paperwork and it was great for him to see people as individuals.

Pindrop is working closer with the Southern CI programme and with this in mind – they are thinking of opening a Wellington branch. With regards to the number of people on the CI list – it needs to be sustainable. Currently 25 people each month are being referred to both NCIP and SCIP. Only 5 implants are being done each quarter year – a total of 20 a year each trust. However with publicity and more funding available this may increase to 30 a year and then more. Sometimes there is extra funding at the end of the financial year and a few more people are done.

Marian asked what the average waiting time was. Lee said there were 7 various categories that come into force that determine where people are situated on the list however it is approximately 2 years. She has been without a job for 4 years and said her life sucks. John (her husband) said he found it hard to communicate with her and sometimes can't be bothered. He said she lipreads lots of the time. Donna said it was very difficult for Marian as she has to concentrate on his lips with 100% of her energy to get information from him.

Di said that not to pussy foot around saying how bad her life was – she suggested having a major meltdown.

Maxine said that she was not to minimise difficulties she was having.

Marian said she had been heavily involved in music and one of her family is doing a Bachelor of Music. 4 years ago she had worked as a manager and because of diminishing hearing had had to give up.

Kerry has been taken off the CI list. She had been reassessed by Auckland University by a trainee and they found she did not meet the criteria. She had not told them that her hearing fluctuates and her eyesight is deteriorating. Lee said it was the first he had heard of someone being taken off the list and was going to look into it. Maxine said that the fluctuating hearing loss was not very common and gave Kerry her details.

There was the suggestion that people who go onto the list feel they are not entitled. As there is a large number on the list the cost of \$50,000 to do it yourself is prohibitive. The availability of partial funding where the equipment is paid by the government and the consumer pays the rehab, hospital and surgery may mean more people can have access. However they need to be aware that they service ongoing costs.

People who sent individual postcards prior to the Forum to Members of Parliament and Ministry of Health officials had received letters.

There was another round of applause to Lee and Nic for putting on the CI Forum.

Louis has now been accepted onto the list. He has worked in computer management and digital support. He is now retired. However over time he has spent long of money on hearing aids and perhaps if a subsidised CI was offered – he may be interested.

The meeting finished approximately 12noon however a number of members stayed behind as they still wanted to discuss various items.