

Auckland Cochlear Implant Consumer Group

Minutes of the meeting held on 20 May at Hearing Auckland (Hearing Association), Remuera, Auckland.

Hosts: Pam and Rodney.

Present: Donna, Viv Welham, Nic, Lyn, Vince, Raewyn, Donald, Des and Gay, Stuart, Patricia Duigan, Maxine, John N.

Apologies: Louis and Mona, Gloria and John, Kerry, Hannah, Maurice and Patricia, Karel, Raewyn Ashdown, David M, Anita and Frank, Di, Rod and Helen, Linda Piggott, Bea, Caroline.

Thanks to Pam and Rodney for providing morning tea.

As Donna had forgotten the key, we all ended up at a cafe and had tea and coffee there. Thanks to Pindrop. Luckily our guest speaker for the day, Cynthia Brown-Mendes, Manager for Hearing Auckland (Hearing Association) had a key and we started at 10.30 with her talk.

Cynthia has been in the position since August last year. She has had no previous background in hearing loss. Her emphasis is on community and family involvement having worked in university (social work) and prisons (young people). Her placement gives her the opportunity to learn and she works 25 hours per week and loves working in the beautiful building. She has children aged 6, 16, 20, 24, 27 and 32.

The Hearing Association began in 1932 within the Health New Zealand system. However all hearing associations are run independently and are their own business. In days past, lip reading classes were held there. Also bridge playing and conferences so there is a lot of history. The Trust has its own building and assets. They still run an audiology clinic, however in close proximity are 9 clinics which offer similar services and are competitive. Hearing Association's audiologist will work 1 on 1 and the advice they give is totally independent. If you go to another audiologist, they may sell only certain brands (and get a commission). They do tests, sell aids, access funding and have a waxing clinic.

They are setting up a charitable arm, as there are lot of people not accessing help. This is a pilot project for people who are unable to afford hearing aids. This is being run through a budgeting service and can also help cover the cost of travel. One lady with hearing problems they helped had 4 children and having food on the table is more important.

The hearing ads on TV are awesome involving whole families. Cynthia said she could relate a number of beautiful stories relating to help with hearing loss.

One wheelchair man needing hearing help was referred and support given for both taxi and hearing aids. They also wish to access rural areas.

Donna: I remember hearing about a farmer who was being assessed for a CI and was queried by a professional as to why he would need a CI. He was only a farmer.

Laurie: They probably thought he had a lot of money.

Rodney: I remember being told that if I could hear on the telephone I would not be eligible.

Nic: Remember when we had a hearing dog lady speak to our group. She said her audiologist told her she would not be eligible.

Cynthia is working with the Auckland University and trying to restructure. They have a 2 year strategic plan and within the Auckland council zone.

Lyn: Is there liaising between Hearing Associations within New Zealand?

Cynthia: We share information. Also too there is the NZ Hearing Association website. We have decided to give up the selling telephone and hearing devices. These services are available through Life Unlimited and other avenues.

Lyn: People who are deaf and have no success with hearing aids. Are they referred to a CI professional?

Cynthia: Yes. Our audiologist is very proactive. So far we have not referred a client to Auckland University. We have an awesome board who are based around hearing.

Lyn: There is a subsidy for hearing aids. How come there is no subsidy for CIs?

Lyn: We need to have committees to band to gather together to help push the government for CIs. Adults who pay for their own CI get no subsidy.

Cynthia: I will look into this.

Donna: I remember when I got digital hearing aids 20 years ago they were \$10,000. I got a subsidy as my children were only 5 and 7 and ended up only paying \$2,000. CIs are \$40-\$50,000.

Laurie: I got my CI through the Government. However if I wanted a 2nd one I would have to pay for it myself.

Cynthia: This is a Government issue and affects a number of health issues.

Nic: This is an international thing. We need to keep in touch with key players. Obviously comes down to a lack of funding.

Donna: I heard of a woman who was given medication because they thought she was mentally unstable and this went on for a couple of years. Then they got her hearing tested and her problem was solved. Also too that a number of people who are in prisons have hearing loss and are misunderstood.

Lyn: The Hearing Association in conjunction with other hearing loss associations need to co-ordinate with each other and put forward a united force.

Laurie: Its really huge being able to hear again. It's an incredible science. It's not ordinary medicine and it's a hugely specialised field.

Maxine: Its good that Cynthia is doing this research. There are a lot of people with hearing loss missing out on support that's readily available. We just about need drivers licences for our hearing aids to make them work.

Crazy that children who have deficiencies get medication, however hearing aids are not funded and cost \$700.

Patricia: Schools test sight and this is Government funded. Buses go around primary schools and check people with hearing problems.

When people have ADHD, they are given drugs. There could people with hearing problems which relate to a processing disorder.

Maxine: We need to have more advocacy and lobbying and get the message out.

Donald: What about teachers training colleges?

There is funding available in the public system for children up to 18 years.

They need to be educational speakers.

Rodney: Hearing aids are getting cheaper.

Cynthia: You can get cheaper hearing aids through your audiologist. People even purchase them online and can be fitted at a clinic. However there is a warranty downfall because of having been purchased from overseas.

Rodney: I know cheaper hearing aids have been available for over 10 years.

Donna: Just like all technology as there is more usage, it becomes cheaper.

Pam: I had a hearing aid on one side and my CI on the other. I purchased a \$4K hearing aid and then three months later lost my hearing and it was no use.

Cynthia: Unfortunately there is no resale value. We make use of old hearing aids and programme them for others.

Stuart: Do you still give therapy, i.e. lip reading classes?

Cynthia: This contract has been given to Life Unlimited. They are run on an as a needs basis and not monthly/weekly which used to happen here.

Lyn: I came here 20 years ago when I wore hearing aids. There were 2 audiologists. When my hearing changed, there was no information given about CIs. It would have been great to have posters around so that when waiting for appointments, information could be gained.

Donna: It would be great to be a one stop shops for all readable information.

Rodney: I went to Dilworth and they were great.

Patricia: Within the ½ hour appointment time frame, there is not enough time to ask questions.

Maxine: I was in a group for many years and services are uninformed. You as a charitable trust need to get the information out to everyone and are in a unique position to do so. Many deaf people are not the most informed and their education may be fragmented.

John: My audiologist said I was beyond their ability.

Nic: The audiologist is the main health professional and could be aligned with the commercial environment. They need to educate, however consumers may be overwhelmed with the information.

Some members said they had asked for information and been rejected.

Viv: I'm being implanted with my CI in a few weeks. My GP did not know anything about a meningitis vaccine that is needed.

Nic: GPs cover a broad spectrum of health issues and refer to others for in-depth information.

Stuart: I went to a clinic that had 2 audiologists. However the clinic is only as good as the audiologists.

Maxine: People need to be informed about what services are available.

Cynthia: Perhaps we could do starter packs and also put up posters.

Maxine: Hearing loss affects people in huge ways – distancing them from their children, their marriage and other families.

Rodney: I remember coming here 30 years ago for lip reading classes.

Maxine: Education is not prevalent in the health industry regarding hearing loss and this is where hearing therapists take over.

Raewyn: Thank you very much for being our guest speaker today. It is great to have a fresh approach and your community involvement will be helpful in your role. I personally enjoyed and appreciated it. Medical people in general and in hospitals do not understand hearing loss. However some doctors understand and are wonderful but they don't know a lot about CIs. Also some doctors forget you can't hear and revert to shouting. Yes, this is a specialised area in treating people with hearing loss.

Cynthia was given a token of our appreciation. This was approx 12noon.

As our regular layout of morning tea, general information and then speaker had been interrupted, Donna gave out information to those who wanted to stay, alerting them to recent information.

Easter Sunday, April 16, Ged Stanley passed away. His wife Zeta had passed away in November last year. They were both stalwarts of the club for the last 3.5 year and it is nice they are together again.

Anzac Day, (April 25) Ellen from Auckland University emailed me. She had not heard of the Stanleys passing until a member had advised her. She sent her commiserations.

Margaret Mulhane who is the Northland leader of CICG will finally get her implant in early June. She has been on the waiting list for 3 years. As a result of the minutes last month advising of Bill Gibson's book, she is getting Whangarei Library to purchase a copy. Meetings are hard to hold because of the large area involved. Generally meetings are in Kaikohe or Whangarei. Everyone on her email list gets the notes for our meetings.

Smoke Alarms.

Remember if you move property, you may need to be reassessed. Contact Life Unlimited who will do a site visit.

Also keep an eye out that your green light is showing on your strobe. If this changes to red, you may need to replace the battery. If it changes to no colour at all – the strobe is faulty and needs to be replaced. Replace batteries in all alarms every 5 years.

Diane Foreman's adopted son who was at that time the youngest recipient at age 2 of a CI graduates from Auckland University. Here's the link:

http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11847909

The SCIP (Southern Cochlear Implant Programme) has produced its April newsletter. Yes, it is 27 pages but it is all interesting stuff. Here's the link:

<http://scip.co.nz/wp-content/uploads/2015/03/SCIP-Newsletter-April-2017.pdf>

Below is a hearing loss simulation. This goes for approximately 1 minute and it would be great to let your family hear it so they can hear the difference. Here's the link:

https://www.facebook.com/EarScience/?hc_ref=PAGES_TIMELINE&fref=nf

Hearing Matters magazine. Autumn 2017 edition out now: Here's the link

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

The meeting concluded approx 12.15pm.