

COCHLEAR IMPLANT CONSUMER GROUP

Minutes of the meeting held on 25 September at Hearing House, Greenlane, Auckland

Present: Donna, Di, Vince, Kerry, Lorna & Grant Austin, John C, Donald, Nic, Lee, Maxine, Karel.

Hosts: Zita and Ged

Absent: Virginia, Stuart, Raewyn Moffitt, Pam Foster, Kathleen Bennett, Raewyn Ashdown, Apii, Anita and Frank, Louis Ho, Fred and Diana Houtman, Rosie Waghorn, Lyn, Gaye Austin (South Island), Laurie.

Opening the meeting by welcoming everyone, Donna said that Donald, Vince and Donna had manned a stand the Pukekohe Ageing Expo on October 10. This has been going for 9 years and is free for charities to have a table and also free for people attending and also free lunch. Lyn had helped set up but was unable to attend on the day. With the support of Nic from the Pindrop Foundation, the cochlear group has attended this for the last 4 years. It is a way of communicating with the Franklin District directly about hearing problems and that there is light at the end of the tunnel if hearing aids are of no benefit. This has been very successful.

Trish Carraher from Life Unlimited had contacted Donna as she had utilised their services before getting her implant. They are upgrading their professional qualification NZQA to Level 6 and want input to meet the advances in Hearing Therapy and the more in-depth role of a Hearing Therapist. Donna may be consulted to make a comment on a draft qualification via email. She suggested to Trish that the cochlear group may get 3 or 4 people to get together to give a varied viewpoint also if required.

Donna made personal contact with Kathleen Bennett. She is on the email list but is unable to attend and has had her implant for approx 2 years.
Rosie has had her implant and is awaiting switch on.

A newspaper advertisement re the 111 St John Ambulance was displayed. They are trying to stop people wasting services as 30% of calls do not need an ambulance. A number of specific questions are to be asked. Donna said it was frustrating because when hearing impaired people are stressed – their hearing may be even worse. This is something that has come to our attention since having Phil Faidley from the NZ Fire Service talk to us. We had found out that the 111TXT run by the NZ Police is not known about widely in the police fraternity. Lee suggested contacting Louise Carroll at The NZ Deaf Foundation for her support in the matter.

Nic said that the conference is still going ahead opening Hearing Week in March 2015. Originally intended to be over 2 days – is now only 1 day. There is to be forums and lots of information for all CI people. We all need to attend to make our voices. The Minister of Health is to be invited.

Lee said that they are unable to get Graeme Clark to come. He is in his early 80s and has lots of international commitments. However he is going to write a letter to the NZ Ministry of Health of the benefits of the cochlear implant. There is the hope he may be able to come over to NZ later in the year. Also too that possibly Jim Patrick is able to come as well. He is the scientific technical officer who has worked with Graeme for 30 years and was able to implement the idea to its fruition.

Last year 128 CIs were implanted. The need is still there to keep ourselves on the radar for funding – as there is a new Minister of Health. The swansong from the last Minister was that children would receive bilaterals.

With 200 adults on the waiting list the hope is that people will not wait more than 2 years – with this reducing.

The current CI is the Nucleus 6 which is a multi-channel CI. This needs no remote and changes settings automatically and is wireless.

30,000 CIs are produced each year by hand.

Maxine started the discussion at 11am.

She was thankful that we still held a meeting on a long weekend as she said people can be even more isolated because of it.

The first topic – heading for a CI – our thoughts.

As Lorna has been on the waiting list – everyone directed their answers to her.

Donna – approach with the hope that anything is better than currently. She noticed an instant change.

Di – 40 years deaf. Relationships benefit – immense relief for hubby. Day to day gets better.

In a forum you are able to participate – and your wider relationships benefit. You are back at the cliff-face and not a bystander.

Nic (Pindrop) – 4 years helping people with CIs. Having a health background and meeting people beforehand and seeing the difference in their lives. Knowing that there is the deaf culture and hearing impaired people do not fit into this and need a voice and need representation.

Karel – 30 years hearing problems, psychologist, minister, then photographer. Income levels up and down. Isolation. Misreading situations.

John C – 16 years CI switch-on.

Maxine – 20 years CI switch-on Feb 2015. Ron Goodie as her oral surgeon. Got her life back.

Ged – Husband of Zita who has had her implant 6 months. Very frustrating trying to communicate.

Zita – Still having telephone problems.

Di – Progress continues.

Donna – Cable TV has some channels with subtitles – some advertised are not available.

She has freeview which has lots of subtitled programmes and is able to tape to her DVD with them as well.

Grant (Lorna's husband) – queried how music is heard as Lorna is a good singer.

Nic – explained how the hairs in the ear are broken and the electrodes are nerve stimulated.

The whole purpose of a CI is to get speech 1st and so is not natural hearing.

Karel – The brain needs to adjust and train. He played the piano and listened with earphones to hear familiar music.

Donna – You may hear only a small amount to start with.

Di – all hearing is a progression and it takes practice.

John C – processors get better and every one has been different (John has had a few CIs)

Lorna – is tinnitus a problem or does it get better. She has it in both ears.

Donna – her left ear was operated on because she had continual tinnitus. As a result when the processor is not on – the tinnitus ramps up. With the processor on – it disappears.

Karel – with the CI and hearing there are plateaus and then sometimes huge gains

Vince – got a CI because of the loss of his job. He had no confidence and became very negative.

Donald – Normal hearing became hard to understand. With the CI – fridges as background noise can be a problem

Zita – found when in malls hearing aid goes off – and CI changes programmes.

This could be down to the same frequency, and the programme changes, or possibly the automatic telecoil switching on.

John C – found in an open layout – there is a buzzing noise.

Karel – anti theft device in Canada went off because of the CI.
Di – had problems with her credit card.

Maxine then brought the conversation back to unusual noises people had heard since having a CI. She remembered when we had Lance Cairns as our guest speaker he said he kept hearing an intermittent noise in his car. He had taken it to the garage a number of times to try to get them to find out what the problem was. He found out himself when he looked in the boot and found his golf clubs.

Karel – working in his studio trimming prints. He kept hearing an intermittent noise. He went upstairs as he thought his wife was making the noise. His wife was not home. He went back and the noise kept happening again. He found each time he cut his print – his elbow kept knocking a small vacuum cleaner next to his desk and switching it on.

Donna – when working for census last year was going around homes collecting papers back. Thought her cellphone was ringing and checked and it wasn't. Looked around and saw the ice cream truck with the music 'greensleeves'. When she was newly implanted with her CI – guys shoes sounded like high heels. When peeling vegetables they made a scraping noise – and said the vegetables were noisy. In the early days she did not hear her battery beep to say it was running out and thought there was a problem with her battery. As her maps were altered she was able to hear the beeps. Hanging our washing on her clothesline wondered whether the neighbours had birds and they seemed really noisy. Checked her roof and there they were – as there was bread on the lawn on the other side of the house.

Di – when she was still wearing aids. She was driving and heard a bad noise – so bad that she pulled over to the side of the road. Looking up into the sky there was a helicopter. Also working in the kitchen and hearing a beeping sound, trying to locate it, and found it was her hearing aid.

Karel – Pen on paper – sounds very scratchy.

Di – chewing food is a new experience as you can hear it in your head.

Donna – said turning pages in a magazine or newspaper are very sharp sounds. Also pouring fizzy drink and hearing the fizzing sound. Cooking steak in the frypan and it sizzling.

Ged – said Zita heard the clocks ticking and it annoyed her, so they put them away.

Donna – found shopping trolleys to be very 'chinky chanky'. She found that if you focused on a sound, it became important. However as soon as you didn't take notice – the sound disappears into the background.

John C – found the 10 pin bowling arena very good. As he has a Nucleus 6 processor, he found it was great to filter out the background sounds with the environment programme. He thought he was getting a better sound than hearing people. Each processor he has had he had to relearn to hear as all processors are different.

Di – everyone has different experiences of the sounds they hear as we are all different.

There is the ability to look up on facebook if you are a member:

www.facebook.com/CochlearANZ where people can ask and answer questions posted.

Karel – What do we term as noise.

Vince thanked Maxine and presented her with a token of our appreciation.
The meeting closed at approximately 12noon.