

## **Auckland Cochlear Implant Consumer Group**

Minutes of the meeting held on 19 November 2016 at Hearing Auckland (Hearing Association), Remuera, Auckland.

Host: Lyn

Present: Donna, Kerry, Vince, Raewyn, Caroline and Heather, John and Gloria, Maxine, Des and Gay, Zeta and Ged, Bea Marquette, Di, Pam, Marian and John, Helen and Rod.

Absent: Maurice and Patricia, Donald, Linda Piggott, Raewyn Ashdown, Nic, Karel, Stuart, Louis and Mona, Michael Lee.

Donna welcomed everyone and thanked Lyn for morning tea. Others had brought along Christmas goodies as well.

Just a note to please make sure you put donations in the tin. It is unfortunate that Donna found out that one meeting we received only \$5. As the request is for a gold coin, we don't think it is too large a donation. Obviously people come along and get distracted, so in future we may send the tin around while the meeting is underway.

Nic had sent Donna a new contact name – Bea Marquette. She is here today with us and has had switch on only three weeks previously. It's lovely to see new members.

The Tauranga Xmas get together was happening today also at 11.30am.

Waikato Xmas 'do' is on Sunday 4<sup>th</sup> December.

If anyone wishes details, let Donna know and she will pass them on.

As a member of Trade Me Donna has a search which sends emails on all things 'cochlear'. A recent notice showed a book on an American lady who is now in her 60s. She had lost her hearing at the age of 6 and had taught writing and art to deaf children. Donna asked the Auckland library to purchase a copy (they bought 2). This book is only 150 pages and is interspersed with prose and verse.

'After being implanted, she realised the amplification and comprehension were two different things: at first all she heard was a soup of sound, a condition known as brain deaf. She soon learned, however that regaining her hearing was a journey of discovery. Gradually the sound soup gave way to the ability to hear some sentences without speechreading.'

Donna met up with Donald last week and he will be back next year. He has been undergoing chemotherapy. He currently has a Freedom processor and may look to getting a N6 processor next year.

Coming across a foundation in New Zealand, Donna alerted members to it. It is from the Oticon Foundation which is a charitable trust and aims to improve the lives of hearing impaired through communication and knowledge. They are committed to finding better solutions to hearing loss and strive to increase public awareness and understanding of hearing impairment. Check out their website and they have some newsletters that may be of interested. Obviously along the lines of Pindrop. <http://www.oticon.org.nz/>

The local supermarket seems to be where CI people congregate. Recently Donna met a CI recipient and talked to her for about ½ an hour. Barbara recognised Donna from a local newspaper front page article. As Barbara lives in Meremere, it was fortunate that Donna was travelling down a few days later and was able to have a catch-up and meet her hubby. Unfortunately they do not have internet so it makes it difficult to get information to them. They did not know of the smoke alarms for CI people and Donna sent them some information and made contact with Life Unlimited on their behalf. Barbara has had her implant for approx 4 years.

Donna spoke to a couple of groups recently, one for deaf and blind people and also to the Huntly BPW about CIs recently. They were both great events and hopefully have more knowledge about CIs.

How many people have logged onto the new cochlear website and received their welcome card? As N5 users have probably noticed, the Hello page shows N6 as your processor. After contacting Simon from Cochlear NZ, he said this was the standard page for all users as this is the current processor. By just selecting the right hand side and your N5, all your details are there including guarantee expiry dates, etc. Donna has put the same question through the website and was able to tell them what Simon had said. As Donna had received a new processor under the 5 year guarantee earlier this year, they had no information about what the processor was she was using. This is being sorted.

Recently through the CICG email, Donna had received a request for information regarding adult lobbying for adult cochlear implants. The information was wanted for a German article. Chris Peters had been the public affairs manager for the Hearing Association 2003-2009 and had made contact with the Southern programme, and they had passed on details of the Auckland group. Donna had re-contacted him after giving him information and found out that he has a cochlear implant and lives in Ngatea. He regularly comes up to Auckland so they may catch up.

Maxine said he was a very influential person and very proactive. He is also a respected journalist.

Zonta is a charity group which can support deaf ladies through sponsorship of education.

Planning for the forum for 2017 is well underway and lots of organisation completed. The date is March 11, 9.30-6pm at the Auckland University (where your CI is programmed). Check out the Pindrop website for more information. <http://www.pindrop.org.nz/> Please note that a large proportion is subtitled so that even if you are on the waiting list, you are not disadvantaged.

Lyn said the aspect of having subtitles meant it was less stressful for people trying to listen.

Lyn then alerted everyone to the fact that if you have a smart phone there is the possibility of talking into it and having subtitles typed in for you. This is useful if sending large texts. It is a small icon looking like an old fashioned microphone. However make sure you do not put the contact or email address in, otherwise it might get sent before you have 'proofed' it. Words like full stop, new paragraph can sometimes be typed.

Di's daughter-in-law is called Teresa and the subtitling puts tee ree sa.

Di then got up to talk about having gone to England and having processor problems on Day 10. Unfortunately this happened at the weekend. She had changed batteries and thought they may have been faulty, so put more in. This did not solve the problem. She had been told to take information overseas of Cochlear contacts in the region she was visiting. Luckily she had friends who were able to phone around for her. They made contact with Thames Hospital in the hope that they could take the processor in to get it looked at. They only deal with processors after a referral from a specialist. Cochlear UK was not open to the public as it was the weekend. Di ended up making contact with her hubby in NZ and contacted Silvia at the Auckland University who sent a referral to customer services Cochlear NZ. She instantly replied to Di to hold tight. Cochlear UK rang immediately and she was able to go and pick up a brand new processor, programmed and ready to go. This is because Di's processor was less than 5 years old. As Di is a paying customer she thought she would have to pay \$13,000 for a new one. She said normally if processors have problems, the orange and green lights can alert you to what the problem may be. However not so good when no lights are showing at all!

Laurie: What about travel insurance?

Di had taken out \$10,000 on processor insurance. And she knows the English system for CIs is a lot different to the New Zealand one.

Rod: Did you find out what was wrong with her processor?

Di: I am due to revisit Auckland University so will ask them.

Rod: is there anything you may have done wrong?

Di has had her processor for 4.5 years.

Marian: NZ cochlear system different?

Di: I know of a British lady who has had problem trying to get help from the New Zealand system because she had received her implant in Britain.

Marian: How long after you made contact with Silvia before you were helped?

Di: Within 24 hours.

Donna: I know over the Christmas/New Year period that the University has a mobile phone which someone takes with them. This is for emergency contact. Perhaps over the weekend the switchboard is sent to someone's private telephone and this means contact is guaranteed.

Di: The processor was organised and luckily pick up was only a 1/2 hour drive away. It was incredibly prompt.

Des: and this is because of the contact with Silvia?

Di: I had made contact with my husband who found Silvia's contact from old emails. As it was on Skype he 'signed' I hear you.

Laurie: Just as well your husband is not deaf as well.

Raewyn: In some places, the email doesn't work. Also the mobile network. This could make contact even harder.

Di: Yes this can be a problem. The great thing was that I was around people who were prepared to help and could do a lot of telephoning for me.

Pam had recently been over to the Sunshine Coast and had to pay an extra \$200 for her processor in insurance. Her sister was meant to come up from Christchurch and go as well. Unfortunately she broke her hip 3 weeks beforehand. She had tons of paperwork for fill out and it took over a month to get a refund less excess.

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Maxine: I went to the last forum and the captioning is voice activated. It is not perfect but its great.

Rod: I have a Captel telephone. Sometimes I am talking about farm business and the machine writes strange words.

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Lyn took over the floor and had produced a 20 questions Christmas quiz. Winners of this were Rod and Helen McAlpine and they received a small gift.

Secret Santa was next and numbers were handed out. As people got gifts, others after could take their gift and the original person had to get another gift. This only happened a number of times, and mostly gifts were chocolates.

John said he had some waterproof covers for CIs which were bought as a pack of 5 and if others would like one, to contact him. He also spoke about the problem with the smoke alarms and the batteries needing to be checked.

Donna said these two points had been brought up at the last meeting and yes it was extremely necessary to check the push button to make sure it worked. This is the main unit, which works the whole smoke alarm system. The batteries say they can last 5-10 years, however there is a fault with the push button unit. The NZ Fire Service is aware of this. They may make a recommendation for a similar system which does not have this problem.

After some general conversation, Donna got everyone outside to take a photo of current members. This is going to be used for promotional purposes. The previous photo had been taken two years ago.

The day concluded approximately 12.20pm.