

COCHLEAR IMPLANT CONSUMER GROUP

Minutes of the meeting held on 24 May 2014 at The Hearing House, Greenlane, Auckland

Present: Donna, Donald, Stuart, Anita & Frank, Vince, Laurie, Zeta & Ged, Kerry, Lyn, Nic, Lee, JayJay.

Apologies: Virginia, Raewyn, Diana, Derek, Kathleen, Joyce.

Host and Hostess: Di and John C

The speaker for the meeting was Scott Johnston, CEO (Chief Executive Officer) of Hearing House.

Hearing House started 10 years ago and there were lots of projects to do. There are currently 20 staff who are passionate and like what they do. They sometimes have to deal with difficult situations.

94% of deaf children are born to hearing parents. Parents grieve for what might have been. There is the need to transform disability to ability.

Bilaterals are available now for children and there is the different ability to develop language. Staff are thrilled with this development. 3 years ago - there was the remote possibility of bilaterals. However Scott felt that adults should be put forward first before children received bilaterals.

In 1999 Sir Patrick Eisdell-Moore and Sir James Fletcher went to Government in Wellington and got \$250,000. They had holidays at East Cape where they hashed out how to get started. Cochlear implants had been around for 20 years - however implants needed therapy. Children are best implanted prelingually - as they have no language and they also need therapy. Kelston was approached for therapy - and replied 'no'. Rotary were approached because they needed to buy a house and in 1998 it was bought and called Hearing House. They went overseas for help and to learn auditory / verbal practice to operate. The Hearing House operated on donations initially - and in 2005 received government funding and the Trust was formed.

Hearing is developed at 20 weeks in utero. So children need access to sound for language development. You need to develop the brain for language to come. The first 3 years - the brain is like a sponge - millions of neurons are developing being stimulated by sound. These neurons are 1/3rd of the size after 3 years.

Implementation of the newborn screening to catch children earlier and the earliest implanted children are at 5 months.

A video of Eila at 5 months old (now 6) showed her focus on listening. If the children listen well - hearing comes.

6 main sounds are focused on. Sign is not offered to babies. Some older children who get implants have sign language.

Children aged 3-5 years are at a significant disadvantage because those early learning years are lost - and traits have been inbuilt. Use it or lose it. Adults deaf from birth should not be implanted. At the age of 5, CI children's receptive language is tested and shows at 6 years.

The aim of the implants is to have independence and be socially included.

93% of deaf children are mainstreamed at age 5 and 76% are 6 months ahead with their speech and language skills.

There are some children with complex issues who may have fragile health, cerebral palsy or have had strokes who are also deaf.

The Hearing House has an intensive therapy for 50 children up to the age of 5-6 years. 200 are in the CI programme with 15 kids in assessment.

The Hearing House has a family-centred approach. However other support staff are: AV therapy, CI audiologist, family counsellor, ECT teachers (preschool), ENTs, AODCs and RTDs, DHB audiologist, Kelston and the University of Auckland.

They are developing a programme called Focus. They feel 25% of children are not being reached. They need to identify and reduce barriers and access. Each family has a customised approach to suit their needs.

Telechat is a new programme instituted. This means using new-age technology - skype. One child in Marlborough Sounds has been using this. This makes it accessible for children to have rehabilitation who live in remote areas. They are improving access to specialised service and allows weekly contact. This is a 12 month pilot rolled out nationally.

They had a Sunshine Residential 3-day out for 12 families in 2012. This allowed parents and children to interact with others in the same situation. This was held at Long Bay.

Hear 4 You - a mentoring programme for deaf and hearing impaired teenagers is another programme. This has 3 interactive programmes. These help to build confidence and leadership and encourages teenagers to pursue goals. There is also a programme for additional problems.

95% of children attending Hearing House have CI implants - while others have had funding for hearing aids. There is special educational available for children 0-8 years and deaf kids get help.

Children are assessed at severe hearing loss to be eligible for CI - so the cut-off is similar to that of adults. They do not need to be moderate or profound and the audiologist and surgeon assess candidates.

Hearing House is in the process of redevelopment. They currently cater for 200 families - and the facilities will change within the next 2-3 years. 2 more houses next door were purchased in 2012 and the facility will be purpose built for mapping, therapy, audiology resource and be multi-purpose. This will be over 12,000 sq.ft. at a cost of \$6.5 million of which they currently have \$3.5 million. This will be 2 levels, have a preschool, lift, office for 26 people, family rooms, lecture rooms which can be interchangeable to 2 smaller rooms or 1 larger room and will retain the garden flow and have a double carpark.

Recently a conference called 1st Voice was held. Information was shared amongst resources across Asia. They gave speeches and prime ministers attended. Ben Smith (NZ) 6 years and profoundly deaf gave a speech. He graduated at age 5 from Hearing House.

With children graduating from Hearing House and going to school - there are assessments done by a specialist teacher to make this transition smooth. This may involve the teacher wearing a microphone with a FM receiver so that the noisy environment of the classroom is reduced.

A lot of families - before bilaterals were available - were purchasing the 2nd CI for their children. Rates were probably at every 2nd child. 50 children are implanted each year. Originally the candidates had to be profoundly deaf - however this has been stretched to severely deaf children to allow more. If children now need 2 implants they will be done simultaneously. In the past when children had been implanted in 1 side - they then had to take this off to get the new side learning how to hear. This separation allowed the brain to work better.

One of our members questioned that 2 profoundly deaf parents had a profoundly deaf child. This is where the grandparents need to step in because the child would not probably develop language well.

A child who was an immigrant with Mandarin as their first language - are taught in Mandarin. At age 3 at preschool - English has been brought in and the language has taken off.

96% of parents choose speech.

Scott was thanked for his fantastic speech and a gift given.

Members continued to socialise and the meeting closed at approx 12 noon.

