

# **A Parents Guide to Cochlear Implants in the New Zealand Southern Zone**



**Written by a parent**



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## Introduction

This guide provides an overview of what parents should expect as they bring their child through the process of getting Cochlear Implants in the Southern Zone. It is written from the point of view of a child being identified as needing a CI prior to them turning 2 years old. Obviously this is not everyone's situation. And there will be variations as each child and family is different. So please use this as an indicative guide, rather than a definitive protocol.

### Our Story

Hi. My name is Sym Gardiner. I'm the father of Katya Gardiner, who you will see in this guide. Katya is our first child. She was born in 2006 in Wellington before newborn screening was introduced. Katya is a bubbly engaging girl. She was very attentive. We had no idea she had a profound hearing loss until she was a little over 12 months. Then we started to suspect something. However she would turn when someone clapped (the standard test Plunket uses).

When she was 15 months we knew something was wrong. I managed to walk up behind her when I came home from work and drop a set of keys on a table behind her. No response. At 18 months we had confirmation with an ABR test.

We tried hearing aids briefly but they provided no benefit. We were referred to the Southern Cochlear Implant Programme and just prior to Katya's second birthday she was implanted with two Cochlear brand implants. We were fortunate enough to have the support of our family and church family, as well as some of our own funds to get the second implant done at the same time.

Katya's right hand scar never really settled. About eight months after the surgery, despite attempts to kill the infection with anti-biotics, one of her implants had to be surgically cleaned. She then had a total of 16 weeks of antibiotics (10 weeks IV and 6 weeks oral). Thankfully this killed the infection.

We are now over four years post implantation. Katya is at school in Year 2 keeping up with her peers. She still needs support. We expect she will be support free by the time she is seven.

For my family, Katya's Cochlear Implants mean she is able to interact with us, her friends and the world just as any other kid. That's priceless!

If you are reading this, you are probably starting out on your own child's Cochlear Implant journey. For me being told our daughter had a hearing loss and then being presented with all this information felt overwhelming. I could not see my way through all that needed to be done. My hope is that by reading this guide, parents who follow us will be able to see the steps, avoid the pitfalls and see that with a couple of years' hard work, your child will be hearing and talking... just like any other child their age.

## The Process

### 1. Identification of hearing loss

Children are a fantastic gift for parents. Unfortunately sometimes children bring challenges. Hearing loss is one of those challenges that affects a very small percentage of children. Hearing loss in children can be caused by a broad array of issues. Most of these issues do not require the use of Cochlear Implants (CIs).

Hearing loss that requires the use of Cochlear Implants will, in many cases, be picked up by the New Born Screening Programme. However a small number of children are not identified and a small number of children develop hearing loss sometime after they are born. These children tend to be identified by parental suspicion, early childhood teachers, GPs and even other family members.

*One challenge for parents is mulling over thoughts of what caused the hearing loss. Many parents look for people or events to blame. Many parents blame themselves. There is no point playing the blame game. It doesn't help you or your child. And you may not ever know as many causes of hearing loss are hard to pin down. What does help is focusing on how you are going to address this challenge.*

### 2. Quantification and confirmation of hearing

There are two approaches to confirming hearing loss – Behavioural audiometry testing and Auditory Brainstem Response (ABR) testing.

An Auditory Brainstem Response (ABR) test is performed on children under 3 months old or on older children where behavioural testing (responding to a sound) is unreliable. ABRs are performed in hospital audiology clinics and may require sedation (not anaesthetic) for older children. The child needs to remain asleep during the ABR. The child is hooked up to a number of electrodes that record brain wave responses to sounds played into the ear. The audiologists look for repeatable brain wave activity when the sound is played.

ABRs or behavioural testing are accessed via a referral from your GP to a hospital audiology department. It may be that an initial visit will be required to check for more common issues like glue ear, although your GP should identify those issues.

At this stage, parents should be connected with an Advisor of Deaf Children (AoDC). AoDCs work for the Ministry of Education's Special Education Group. Their role is to provide advice and guidance for families of deaf children, particularly from an education perspective. They should also help you navigate through this process of getting a CI.

### **3. Trialling of Hearing Aids**

When a hearing loss is identified, typically hospital Audiologists will recommend trying hearing aids. This is to try to see if a hearing aid will give the child a useful level of hearing. For moderate hearing loss, hearing aids function well. For children with severe to profound hearing loss, the hearing aid may provide some stimulation of the auditory nerve, which is useful in the very short term. However hearing aids tend to be inadequate to provide good access to language for children with severe to profound hearing loss.

Audiologists in NZ are beginning to use ABRs more to quantify the hearing loss. The trend overseas is to produce an audiogram from the ABR. This allows children with profound levels of hearing loss to skip the hearing aid stage and move directly to CIs.

For parents, hearing aids are quite challenging. They are uncomfortable for the child and they are fiddly to put on. Audiologists tend to want to see a couple of weeks of solid hearing aid use and continued unusable hearing levels before referring a child to the Southern Cochlear Implant Programme (SCIP). The protocol says the trial should be 12 weeks. However audiologists tend to be reasonable and refer on if there is no immediately (at a 2 week check-up post fitting of the hearing aids) observable benefit.

As soon as you have a confirmation of a hearing loss, you should apply for the Child Disability Allowance from WINZ. You will need the form endorsed by your local doctor. It is about \$90 a fortnight. Put it in a bank account. It will be needed in 5-7 years time for a CI upgrade. You may also be eligible for a Carer Relief Allowance. Again, check out WINZ for more information. Both allowances are not means tested.

### **4. Formal CI assessment at SCIP**

The Southern Cochlear Implant Programme (SCIP) is based in St George's Hospital in Christchurch. The child and generally one caregiver will be funded to travel to SCIP. The Ministry of Health (MoH) pays for all travel and accommodation. Additional people may travel with the child but they will generally need to arrange their own travel and pay any marginal cost of accommodation. Transport to and from the airport in Christchurch for the child and caregiver is provided.

The formal assessment consists of two days of testing and observing the child and providing information to the caregiver(s). Part of this time will be to show you a CI and explain the features. The people you are likely to meet include the Audiologist, Habilitationist and Surgeon.

### **5. CT and/or MRI**

A final step before confirming the offer of a CI is to have a CT (Computed Tomography) scan and/or MRI (Magnetic Resonance Imaging). This step is to ensure the cochlea is properly formed, the auditory nerve is formed and both are suitable for a CI. The child is anaesthetised and the CT performed. Most major hospitals have CT equipment. If an abnormality is detected an MRI may be sought for a more detailed image to be obtained.

CIs are still an option for children with malformed cochleas. However a lack of an auditory nerve makes a CI not viable. For malformed cochleas specially tailored implants may be required.

## 6. Offer of CI

If a child needs a CI, they will receive at least one through government funding. There is no waiting list for children and there is a desire to get on with the job – the sooner the better. SCIP will formally offer the surgery and a date will be arranged with you. Be aware that a number of people are required to perform the operation so it can take a few weeks to schedule the operation.

## 7. Key Decisions

Once the offer is made, parents have some very important decisions to make.

### a. Yes or No to a CI

The first decision is whether to go the CI/Oral language way. Some parents, particularly those who are deaf themselves and live in the sign language community, may decide they want to raise their child in this community without a CI. However well over 95% of parents chose to go with the CI option.

The choice is about allowing their child the ability to fully partake in a world that is predominately hearing based. Some key drivers for that decision include:

- Safety – being able to hear danger, warnings, etc
- Giving your child the option of hearing. This option reduces as the child gets older and older. Ideally implants should be done before the child turns 2 – the earlier the better.

### b. Bilateral or unilateral

The second big decision is whether to go for two implants or one. The NZ government funds currently only one. For a second implant installed later you need to be budgeting on approximately \$50k. If it is installed at the same time as the first implant, you need to budget on just \$30-40k. This is still a lot of money. However there are significant benefits to having two.

This web page sets out simply the benefits.

<http://2ears2hear.kiwi.nz/bilateral-cis/bilateral-benefits/>

Most international programmes offer two as standard.

If it is at all possible, two should be done.

You should talk to SCIP about how they can help with fundraising. Also look at

<http://2ears2hear.kiwi.nz/resources/how-to-fundraise/>

### c. Brand

There are four main brands in the world. SCIP offers two of these: Cochlear and Med-El. Both brands are roughly comparable.



Cochlear's Nucleus 5 processor (often referred to as the N5)

Cochlear has 60-70% of the world market and is Australian. Med-El is much smaller in market size but has a technically very good implant. Med-El is Austrian.



Med-El's Opus 2 processor with the XS battery module

There are a number of resources available for making this decision. Either brand will do the job. Both are very reliable. Both have excellent support.

The key resources to consult are:

Cochlear's website

Med El's website

The manufacturers are constantly developing and improving their products. Both brands provide backwards compatibility for new processors to work with older implants. Both have strong commitments to providing life long support.

A comparison table is included later in this guide.

#### **d. Pure AVT or mixed AVT/NZSL**

Another decision is how you want to approach the therapy that will be required to allow your child to use the implant and to catch up their peers.

Some people choose to use a mixture of NZ Sign Language and Auditory Verbal Therapy (AVT). The NZSL allows communication earlier, can provide a framework for language and provides a fall back if the CIs fail (although only communication with those who know NZSL).

Other people use purely AVT, choosing to focus solely and intensely on verbal communication. The argument goes that there is a heap of work going to be required to learn to listen and speak, and then catch up the child's peers. So it is better to focus on just learning one language rather than have to learn two.

There is research supporting both approaches although the pure AVT results tend to be more consistent.

#### **e. Lead caregiver therapist/team coach**

Someone is going to have to put a heap of effort into working with the child over the next few years. Whether it be attending a large number of tuning sessions at SCIP, managing the CI equipment, ensuring batteries are changed, attending specialist appointments and most importantly of all, become the child's primary language teacher/therapist. It really makes sense for one caregiver to lead this and have their hands on everything.

The Southern Zone model is currently designed around an implicit assumption a parent will, in addition to this work, take on the role of coordinating all the different people and agencies working with their child. Currently a child could have people from SCIP, the Ministry of Education, van Asch Deaf Education Centre and education providers like Kindergarten or school working with them. There could be multiple people under each of these agencies involved. However no one 'professional' is responsible for the coordination of all this activity and resource. Nor seeing that it is put to good effect.

In a two-parent family, having one stay-at-home parent is going to be the best approach for the first few years, particularly for pre-school kids. This may not be possible so each family needs to work this out for themselves. But if it is at all possible, then have one parent stay at home.

### **8. Pre-surgery**

All CI kids need to have a pneumococcal disease vaccination prior to the surgery. However this tends to be part of children's vaccination schedules so it is a matter of making sure that it has been covered off.



## 9. Surgery

The surgery involves an overnight stay in the hospital. Generally you will arrive on a Wednesday morning, surgery on Thursday and head home either on Saturday or Sunday.

When packing, make sure you have/acquire the following:

- A favourite toy etc (things to provide security)
- A new toy or something special that your child will love
- A few other bribes
- Button up shirts with loose fitting sleeves (non-button up shirts won't get over the head bandage and the sleeves need to be loose to get over the IV line)
- Button up pyjamas (same reason)
- Extra clothes in case there is a bad reaction to the anaesthetic (very rare)

You will stay in Ronald McDonald House (RMH) in Christchurch. It is a very nice facility. You do need to provide your own lunch and dinner food, although sometimes dinner is provided. Breakfast is provided. RMH has buggies, cots, internet, the best kitchen you have ever seen, toys... pretty much everything you need. It is worth checking out their website before you go.

<http://www.rmhsi.org.nz/>

There is a supermarket near St George's in the Merivale Mall where groceries can be purchased.

The day prior to the surgery you will have a meeting with the surgeon. The surgery is at St George's Hospital. It is the normal nil-by-mouth which you will probably be use to with the sedation and anaesthetic of the ABR and CT/MRI.

Parents need to get away while the surgery takes place. It takes around 2 hours per CI and is just too stressful to sit and wait. The surgeons will call you once the implant(s) are installed. There is plenty of time to return before your child wakes.



Prior to surgery

One parent will need to stay the night in St Georges. Expect your child to be unhappy when they wake up (although a few children wake up fine). They will probably want to eat and then go to sleep. Most children are back to their normal selves the next morning.



Post surgery – note the grim face and IV line in the left hand

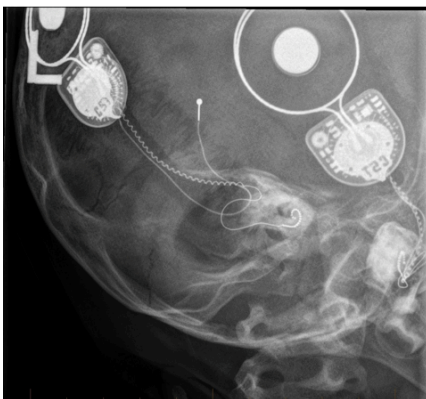
If your child is walking, you should be aware that they may take a couple of days to regain their balance. Most of your balance comes from the cochlea. The surgery can disrupt this for a while. It will come back. In the mean time, they may need a bit of hand-holding, particularly with steps.



The next morning – back to normal.

There will be a number of anti-biotic injections post surgery to minimise the risk of infection from the surgery.

An x-ray is needed to provide a base record of where the implant is placed. This is taken before the child is discharged. One parent will need to hold the child still. Pregnant women can't do this because of the radiation.



X-ray of bilateral Cochlear implants

Then the child (and parents) can return to RMH. You will need to stay a couple of days before being allowed to return home. RMH will hold your room while you are in hospital so you can leave your belongings in your room and the parent not staying in hospital has a place to stay. This means you only need an overnight bag for the hospital stay, which is very handy.

During the surgery the implant may be tested. This is how the surgeons know the surgery has been successful.

A final visit to the surgeon is required to give the all clear. Then you can return home.

## 10. Post Surgery

The bandages can come off roughly after 3 days. They should be removed if they are still on after 5 days. Children tend to pull them off.

It is important to stop the child scratching the wound. Lots of sun is good for healing. A bit of antiseptic cream with an anti-itch agent in it is also good (ie Medicreme)

It is important to watch for infection. Any sign of infection (redness or a temperature) should be reported immediately to your local doctor (GP) and SCIP. You should insist on your GP communicating their assessment with SCIP. In most cases you should get referred to a local Ear Nose and Throat (ENT) surgeon for a more specialist assessment than a GP is able to provide. Infections are serious!



This is a very bad infection and required 4 hours of surgery, 10 weeks of IV antibiotics and 6 weeks of oral antibiotics.



This is what the infection started out as.

The scar and implant site can take a considerable amount of time to fully settle. The scar tissue under the skin can take months to shrink and stabilise. The scar itself should lose its redness much more quickly.

### 11. Switch on

Switch on happens about 2-3 weeks after the surgery, when the scar has healed sufficiently. It generally takes two days.

Essentially the implant is tested and the electrodes activated at very low power levels. At this stage it is about introducing the child to the CI rather than having them hear people speak.

There are generally two sessions each day – an audiology and a habilitation session respectively.

There is also a visit to the ENT surgeon to check the scar and the dissolving stitches.

### 12. Tuning process

Over the course of the next year, a number of visits to SCIP are required as the CI(s) are slowly brought up to a stable hearing level. The following table is a standard programme.

Visit	Time after Switch On	Purpose	Duration
1	2 Weeks	Raise the level of electrodes	2 days
2	4 Weeks	Raise the level of electrodes	2 days
3	8 Weeks	Raise the level of electrodes	2 days
4	12 Weeks	Raise the level of electrodes	2 days
5	24 Weeks	Raise the level of electrodes	1-2 days
6	36 Weeks	Raise the level of electrodes. MAPs should be close to stable.	1-2 days
7	52 weeks	1 year post switch on check. MAPs should be close to stable.	2 day
8	+1 year	Annual Checks	1 day

At the switch on and the first 3-4 visits the CI will have four programs installed, each incrementally stronger than the first. The parent's job between each visit is to progressively move your child up from P1 to P4. Then at the next visit, P4 will be moved to P1 and 3 new and incrementally stronger programs will be loaded. You can think of it as slowly ratcheting up the volume.

It is important to take this process slowly. Be prepared to drop the program down a level in order to keep your child still wearing the CI(s). Some days a child will tolerate higher levels than other days.

When putting the CI(s) on in the morning or after a sleep, always start on the weakest program. Try to avoid having loud noises when you are doing this (like dishwashers, yelling siblings, etc).

Each of the visits to SCIP tends to consist of 2 sessions each day. One session will be audiology, which is the tuning of the CI(s) or testing hearing levels. The other session will be habilitation, which is a therapy session. You will do overnight trips until you can reliably get the tuning/testing done in one session.

The audiology session will consist of mapping and testing. The mapping goal is to create programmes in the CI that allow the child to access as much sound comfortably as possible. The testing goal is to assess the level of hearing the child has at different frequencies.

Additional visits will be made if necessary to get the maps stable.

### **13. Therapy and support pre-3 years old**

Pre-3 year old therapy and support is provided by SCIP and the Ministry of Education's Special Education Group.

The principle contact is your local AoDC. In more major centres you may also be allocated a Speech Language Therapist (SLT). AoDCs are meant to be trained to provide this support and therapy. However they are not trained and qualified in AVT therapy. The level of competence varies greatly. You should expect to receive at least one visit every two weeks. Visits should be 1-2 hours.

SCIP provides AVT therapy when you visit their offices (Christchurch and Wellington), via SKYPE and with regional visits approximately once every 3-6 months. It is highly recommended to join the SCIP SKYPE-based AVT therapy programme.

In addition, parents are strongly encouraged to connect with other families who have children with CIs. AoDCs should be able to facilitate this.

Parents should also join the New Zealand Cochlear Implant Group facebook page to connect with other parents and CI users. Through such groups you will get encouragement (which is often needed) and hopefully a mentor (who is a little way ahead of your family in this process). SCIP also operate a facebook page.

Children who are in an early childhood centre should have an Individual Education Plan (IEP) developed at least every 6 months (preferably every term). The AoDC should lead this process. Parents should ensure they are happy with what is recorded in the IEP and should ensure SCIP receive a copy.

Make sure that that your goals and aspirations for your child are recognised in the IEP. Never let the local "professionals" talk your aspirations down. Many in the deaf education sector operate with a mindset that deaf children will not be able to achieve at the same level as other children. This is old fashion thinking that does not recognise the impact of CIs and modern therapy approaches. You do not need to accept this. CI children should catch their hearing peers. SCIP will support you in holding to these aspirations.

Unfortunately to access the support that you and your child need, you will have to become an active advocate for your child. This does not mean that you have to be aggressive. However it does mean that you will need to be firm on occasions. Listen to the “professionals” and then make up your own mind. And never shy away from asking and communicating your child’s needs.

Children who are in an early childhood centre can also access Education Support Worker (ESW) hours through their AoDC. This can come out of the IEP process. ESWs are like Teacher Aids in a pre-school context. Again, ask about these resources.

#### **14. Therapy and support post-3 years old**

After age 3, if your child is in an early childhood centre (like a Kindergarten, crèche, etc) you are able to access van Asch Deaf Education Centre (DEC) Resource Teachers of the Deaf (RTD). Your AoDC should do the referral to van Asch before your child turns 3 so that you can access an RTD the moment your child turns 3. You do not need to wait until the beginning of the next term or year.

You should expect 2- 3 sessions per week, each lasting about 1.5 hours. The amount of time varies a bit depending on the resources available in your location and the demand for the service. You should actively seek as much time as possible from your RTD. RTDs can be very useful, although the quality varies greatly.

RTDs should support your teaching/therapy choice in the early childhood centre and follow the IEP. ESW hours can be accessed in addition to RTD time. You should try to get as much resource as possible, provided the people involved are competent. If they are not, you will need to advocate to remedy this.

#### **15. Therapy and support post-5 years old**

IEPs can continue to be critical once a child starts school. The school should take over developing these from the AoDC and the AoDCs involvement will taper off.

Prior to starting school (at about 4.5yo) you should start work on submitting Ongoing Resourcing Scheme (ORS) funding and other resourcing requests. Be prepared to challenge any rejections you might get. As a CI user your child is eligible for ORS funding regardless of how well they are doing. The Ministry of Education’s ORS guidelines state this.

Your AoDC should help you access Teacher Aid (the school equivalent to the ESW) funding as well as the ORS funding.

Before your child turns 5 you should have all this in place.

ORS funding is used to provide Resource Teacher of the Deaf time. This is typically provided by van Asch Deaf Education Centre. However the funding is allocated to the child. It can be transferred from the default provide to other providers (such as your child's school). There are some rules around this but a number of parents do this because the resource can be configured more optimally for their child.

All that said, if your child is identified early, implanted early and has had a solid run at therapy, they should be entering school on a par with their peers. However it is good to get all this support lined up. But look to see how much they actually need.

### **16. Post Therapy and support**

The goal of all CI parents will generally be to see their child operating in the school environment without the need for support. In many countries, intensive therapy is provided to CI children. Intensive therapy should see a CI child catch up the time they haven't heard in the same amount of time they have been hearing (ie if they didn't hear for 2 years they should be caught up with intensive therapy by the age of 4 – 2 years intensive therapy). Unfortunately intensive AVT is not available in the Southern Zone. So children can struggle to enter school without needing some support.

Over time the amount of support should be able to be dropped until no support is required. Resourcing like ORS can be placed on hold and re-activated if necessary. Ultimately it can be cancelled as your child operates independently in the school system with no support.



## **Things you should know and a bit more detail**

### **1. Simultaneous Bilateral CIs are best**

A single CI will provide a lot of hearing. But it won't be adequate on its own in an early childhood or classroom setting. Unilateral CI users typically require an FM system which gives the teacher a microphone to talk directly into the CI. FM systems are notoriously fickle although they are provided free. A second CI can eliminate the need for an FM system.

Bilateral CIs are best installed at the same time. If there is a gap the first CI implanted may become dominant. At the very least, additional habilitation work will be required to bring the second ear up to the same level as the first and it will cost you \$10-20k more. If habilitation work is not done on a new second CI or the gap between the first and second implant is large, significant benefit will still be provided by the second CI. But it is likely to always be weaker than the first CI, reducing the overall effectiveness of hearing.

Bilateral CIs provide much louder and clearer hearing both in normal conditions and especially in noisy conditions. Children develop language faster and more clearly with bilateral CIs. Children with bilateral CIs are also shown to be more socially engaged and aware.

### **2. The big limitations of CIs**

The biggest limitation around CIs has traditionally been that they are not waterproof. The manufacturers are in the process of addressing this with their latest models.

Otherwise they can be worn anywhere, including through airport security.

### **3. What do CIs cost you?**

In NZ the govt funds one CI per child, except where the child is losing their hearing from meningitis (these children get two implants as once the meningitis impacts it is very difficult to install a CI). The govt funds all costs for that one CI including upgrades, batteries, spares, fault fixing, consumables, SCIP visits... everything up to the age 18. Thereafter only upgrades are funded.

If you chose to pay for a second implant, SCIP currently funds everything but the upgrades. However if you bank the Child Disability Allowance, after 5-7 years (when the govt funded upgrade is due), you will have enough to fund the second CI (which you own).

The only cost that families must bear is insuring the processors (both the govt one and your one if you have a second). You will need to add and specify the just over \$10k processor on your House and Contents insurance. For those with bilateral implants, you should consider insuring one of the implants as well.

#### 4. What's the best implant?

Each implant brand has its pros and cons. Cochlear and Med-El have taken quite different approaches to the way they technically work. The following is a simple comparison.

<b>Issue</b>	<b>Cochlear</b>	<b>Med-El</b>
Number of electrodes	22 contacts plus 2 earths	12 pairs (24 contacts in total)
Maximum Stimulation Rate	32kHz	50kHz
Independent Power Sources	Single – a single electrode can be 'fired' each cycle	Multiple – any combination of the pairs of electrodes can be 'fired' each cycle
Implant impact rating	1 Joule	2.5 Joules
Remote Control	Two way remote	One directional remote
Ruggedness	Up to IP57 rating with rechargeable battery. IP44 with standard batteries Swimmable with Aqua Accessory Cochlear are renown for their tolerance of abuse.	There are currently some issues around cables. These cables are due to be updated with a more rugged design.
Weight	Rechargeable Setup: 10.9g  Standard Setup: 13g (2 battery)	DaCapo Setup: 10.1g Standard Setup: 12.4g (3 battery) XS setup (2 battery) is 25% lighter than the standard setup
Processor Size	9mm thick	8.7mm thick
Battery Life	Up to 60 hours (Standard)	Up to 90 hours (Standard) 60 hours on XS Battery Pack
Wearing Options	Standard Battery Pack (2 battery) No equivalent Rechargeable Battery System LiteWear System (2 Battery on back) No equivalent	XS Battery Pack (2 battery) Standard Battery Pack (3 battery) DaCapo System (rechargeable battery) Children's Battery Pack (3 battery on back) Baby/BTE ActiveWear (full on back – no ear)
MRI Support	Up to 0.2 Tesla – no compression bandage required 0.2 Tesla to 1.5 Tesla – compression bandage 1.5 Tesla to 3 Tesla – surgically remove magnet	Up to 0.2 Tesla Magnet not surgically removable
Support	Cochlear have 60-70% of the world CI market. They are present in more countries. They are Australian based.	Med El provide worldwide support but have a smaller number of accredited clinics. They are Austrian based.
Warranty	5 years on processor 10 years on implant	5 years on processor 10 years on implant
Options for malformed Cochleas	Contoured, Straight or Split electrode arrays	Med El will custom make an electrode array based on the MRI/CT scans

There are many other factors that could be compared. However the two models are very similar to one another in these factors. Most importantly, outcomes for normal patients tend to be similar.

SCIP supports both brands.

## 5. Medic Alert Bracelets

You should get a Medic Alert bracelet for your child. Once a CI is implanted, your child can't have an MRI without proper preparations. If they do, without appropriate preparations the implant(s) can be torn out of the child's head. Having this happen is obviously bad.

So medical professionals need to be able to tell your child has CIs even if your child is not wearing their processors or is not able to tell them (ie. is unconscious).

SCIP provide all parents with a form for such a bracelet. There are also international providers who have a broader array of designs.

## 6. CI Terms and Acronyms

There are a number of terms and acronyms used in CI circles.

CI – Cochlear Implant

NZSL – New Zealand Sign Language

SCIP – Southern Cochlear Implant Programme

RTD – Resource Teacher of the Deaf

AoDC – Advisor of Deaf Children

MoE – Ministry of Education

GSE, SES, SEG – Group Special Education (part of the Ministry of Education)

ORS – Ongoing Resourcing Scheme

DEC – Deaf Education Centre

Bilateral CIs – one CI on each ear.

Unilateral CI – one CI on one side of the child

Simultaneous Bilateral CIs – having two CIs installed at the same time

Sequential Bilateral CIs – having a second CI added later

Cochlea – the shell shaped part of the ear that converts physical sound into electrical signals for the brain

MoH – Ministry of Health

ESW – Education Support Worker

Habilitationist – Qualified and experienced AVT therapist

AVT – Auditory Verbal Therapy

Total Communication – A mixture of sign language, AVT, etc all used in conjunction

FM System – a system where a microphone wirelessly broadcasts to the CI. The microphone may be used by a teacher. It allows the teacher's voice to appear to come from the most optimal position regardless of where the teacher is.

TA - Teacher Aid

ABR - Auditory Brainstem Response

## 7. Really Good Resources

There are some really good resources. Many are people's blogs or websites. As such they can change rapidly. At the moment these are good resources:

[www.2ears2hear.kiwi.nz](http://www.2ears2hear.kiwi.nz)

[www.cochlearimplantonline.com](http://www.cochlearimplantonline.com)

[www.medel.com](http://www.medel.com)

[www.cochlear.com](http://www.cochlear.com)

[www.cochlearimplanthelp.com](http://www.cochlearimplanthelp.com)

new Zealand cochlear implant group – facebook (closed group)

cochlear implant online – facebook

parents of children with cochlear implants – facebook (closed group)

cochlear implant experiences – facebook (closed group)

southern cochlear implant programme – facebook (closed group)

<http://www.listeningandspokenlanguage.org/> (and go to the “families” section)

<http://funnyoldlife.wordpress.com/>

<http://symgardiner.blogspot.co.nz/search/label/Cochlear%20Info>

<http://emilysheartandhearing.blogspot.co.nz/>

<http://www.youtube.com/user/PipelineMedia1> - two very inspiring videos

## 8. How do I read an audiogram?

Check out this web page:

<http://www.ehwhathuh.com/2010/11/reading-audiogram-basics-explained-in.html>

## 9. Batteries

Your child's CI will either come with rechargeable batteries or SCIP will supply you with disposable batteries. You will end up going through a lot of disposable batteries if this is the option you take.

The batteries can be recycled through Bay Audiology. They provide little boxes for collecting them in. This is useful as kids seem to like to eat them (maybe because they are shiny and the size of a lolly. Another benefit is that Bay Audiology make a donation to SCIP based on the number of kilograms of used batteries they receive.

SCIP has a small supply of these boxes.

### **10. A couple of pointers to AVT therapy as a parent**

This therapy approach is based around the parent/caregiver providing a lot of input into the child. However it is important to know that there is quite a lag between the effort you put in as a parent and what you see come out in terms of speech from your child. What tends to happen is that you will see small developments spaced quite far apart. The gap between a development can be quite trying for parents. These gaps get smaller and smaller until you are seeing developments all the time.

It can be quite useful to keep a list of words and phrases that your child can say. Keep it in chronological order. It is useful to share this with other people who work with your child.

Anything that exposes the child to language and sound is good. Some good things to do include:

- Read books to your child. It doesn't matter at what stage you are (even pre-surgery), reading books is hugely important. It exposes the child to lots of language. Dr Seuss books have particularly good language in them, but any book is good.
- Do the grocery shopping with your child. There are lots of different foods to talk about. Lots of colours of packaging. Lots of people. Lots of talking opportunities.
- Experience different sounds. Hearing is more than just language. Expose your child to the sounds of wind, birds, cars, aeroplanes, trucks, etc. etc. If they have bilateral CIs, expose them to moving sounds like aeroplanes and cars.

Finally... expect your child to catch his/her peers. For most CI children who don't have other medical issues this should be the goal.