Transforming lives: Cochlear implants in New Zealand

Briefing to the incoming Government

November 2020

NCIP

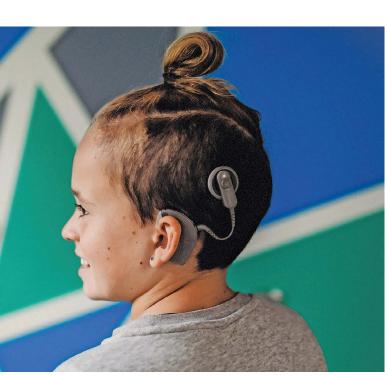
Northern Cochlear Implant Programme



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Hear things differently

"The day my cochlear implant was switched on was one of the best days of my life. **I could hear my kids.** I had never heard anything my three-year-old said, ever. I just felt so full of hope." "Benji has always loved his hip hop dancing. To see the joy that he gets from music and dancing is amazing. That wouldn't have happened without his cochlear implants. It really is the difference between sound and silence."



Benji Earl.

Who we are – New Zealand's two cochlear implant programmes

The onset of total and permanent deafness can happen to anyone at any time. It is not part of the ageing process, but a serious disability usually caused by disease or genetics.

A healthy diet and exercise won't prevent it. There is no pill that will improve it.

A cochlear implant is the last and only viable treatment that can restore hearing. For many the technology is considered a medical miracle by recipients of the devices, including their family and friends who support them.

For almost twenty years both the Northern Cochlear Implant (NCIP) and Southern Cochlear Implant (SCIP) programmes have delivered cochlear implant services both on behalf of the public health system and to a number of private patients.

As not-for-profit charities both programmes aim to keep our fees and costs to a minimum in an effort to make cochlear implant technology accessible to as many people as possible.

Cochlear implants transform lives.

- New Zealand's two cochlear implant programmes are a mix of audiology, surgery, and rehabilitative care for new and existing cochlear implant users.
- We provide visiting services to those in pre-schools, schools and in the regions.
- Demand continues to grow.
- Throughout New Zealand we care for **1,302 adults** and **512 children**.
- We care for cochlear implant recipients for life.
- NCIP and SCIP are the only two Ministrycontracted cochlear implant providers in New Zealand. Both charities receive some funding by the Ministry of Health to provide public cochlear implant services to children and adults.
- Based on population numbers, NCIP cares for adult and paediatric patients north of Taupō, while SCIP cares for patients in those regions south of Taupō.
- NCIP and SCIP perform all cochlear implant assessments, arrange surgery, activate the cochlear implant, administer adjustments and provide post-implant rehabilitation services and care for life.

How we help

We are dedicated to helping children and adults with severe to profound hearing loss, who gain minimal or no benefit from hearing aids.

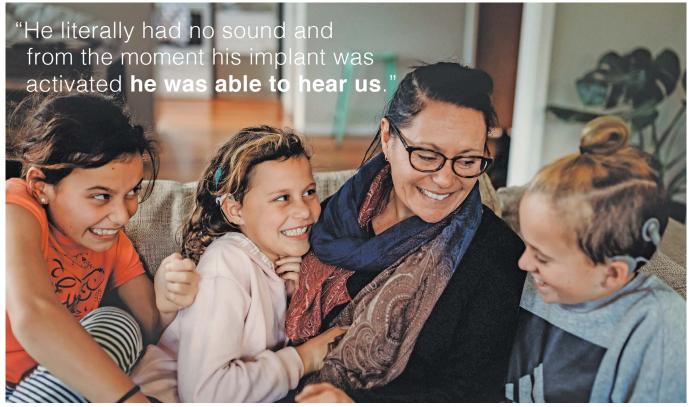
The benefits of a cochlear implant for a profoundly deaf person are huge. A cochlear implant connects, or reconnects people with home, school, work and their communities. Our specialists support the journey from initial assessment through to post surgery audiology, rehabilitation and speech and language therapy.

Those who receive cochlear implants are never discharged from our care. We look after their needs for life.

Unfortunately, demand for adult cochlear implants exceeds the amount of funding available. This means hundreds of New Zealanders are stuck in a silent world. This includes parents who can no longer hear their children's voices, talented professionals who are now unemployed, and people who are isolated in their homes because they can't communicate. Occupations of people on the waiting list for a cochlear implant include nurses, engineers, army personnel, teachers, bankers, butchers, farmers, factory workers, highway maintenance, business owners and retail workers. Many have had to leave their jobs due to their hearing loss, and are now reliant on benefits.

ADULT NEED CONTINUES TO GROW

- Demand, particularly for adults, has grown considerably but only 40 adults nationally receive government funding for a cochlear implant every year.
- Today, there are 240 eligible adults on the waiting list. Based on current referral rates there could be 500 adults waiting for a cochlear implant in as little as four years.
- Since the inception of the programmes, a number of adults eligible for a cochlear implant have died while still awaiting funding.
- Cochlear implants are not covered by health insurance - either you are one of the 20 percent lucky enough to be funded, or you pay \$50,000 to have the procedure privately.

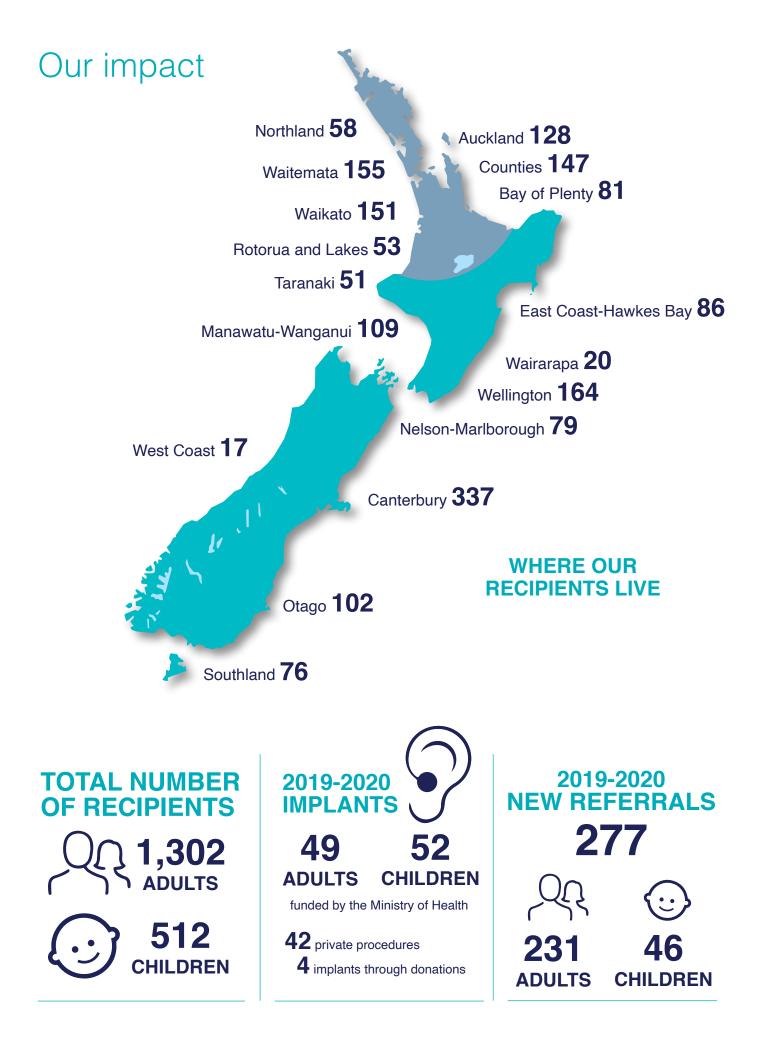


Nicola Earl with her children (from L-R) Olivia, Sadie and Benji.

Liv coming into my life was one of the best things to ever happen to me and I proposed to her on her birthday six months after my switch on. She said yes and we are looking forward to our wonderful life together. Advice I would give anyone embarking on this journey is to be brave and take it one step at a time.

"**My life has changed** so much in the year since I had my switch on."

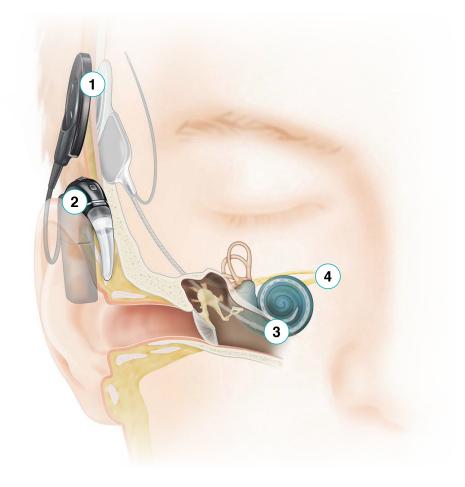
Scotty McLachlan and his fiancé Liv.



How CI technology works

A cochlear implant bypasses parts of the ear that no longer work properly by sending signals directly to the hearing nerve.

- 1. Microphones on the sound processor pick up sounds and the processor converts them into digital information.
- 2. This information is transferred through the coil to the implant just under the skin.
- 3. The implant sends electrical signals down the electrode into the cochlea.
- 4. The hearing nerve fibres in the cochlea pick up the signals and send them to the brain, giving the sensation of sound.





Luke Stade.



There are people in great need whose lives are limited by profound hearing loss. There is a solution for many and that solution is a cochlear implant.



How we're funded

Together NCIP and SCIP are funded **\$8.4 million per annum** by the Ministry of Health. This funding meets the cost for bilateral implants and support services for children, including pre-school and school visits across the country.

We also provide services through visiting clinics and outreach to regional sites throughout New Zealand.

While government funding for children is currently meeting demand, only 40 cochlear implants per year are funded for New Zealand adults (those aged over 19 years). Today, there are 240 adults on the waiting list.

Despite the ready availability of this proven technology, many adult patients approved as suitable candidates are not able to access a Ministry-funded cochlear implant due to lack of funding.

Both NCIP and SCIP dedicate hundreds of hours reaching out to funding bodies and the community in efforts to raise additional funds. We want to do all we can to lower the patient waiting list, support ongoing patient care at low or no cost, and better support costs associated with implants, such as trips to appointments, equipment and specialist care from audiologists and rehabilitation experts.

Ultimately, we'd like to broaden our care to the regions through visiting clinics, patient appointments using remote technology, and taking experts to where they are needed.





- Hearing aids become ineffective when the hearing loss is more than severe. A cochlear implant is the last and only viable treatment that will restore hearing.
- New Zealand lags behind other OECD countries in terms of adult cochlear implant funding – including in the UK and Germany
 - In 2017, 547 Australian adults received cochlear implants¹. On a per capita basis, this is more than twice the numbers funded in New Zealand.
 - Furthermore, in countries such as Brazil, cochlear implants are guaranteed to all ages through the national health system².

2 https://www.researchgate.net/publication/5616235_Audiology_in_Brazil

Sadie Earl.

¹ http://hcia.com.au/hcia-wp/wp-content/uploads/2015/05/Social-and-Economic-Cost-of-Hearing-Health-in-Australia_June-2017.pdf



Ricky McLeod.



"To me it is a miracle. It really makes you realise how important it is that **more people can access** this technology."

Ricky's story – leaving a life of isolation

Ricky McLeod (opposite) is profoundly deaf. For the first time in 40 years he's just heard the sound of his own voice – thanks to a cochlear implant.

Ricky lives by himself in the small North Island community of Raetihi. Before he received his cochlear implant, his profound hearing loss made it extremely difficult for him to communicate with others. This led to a lack of confidence, with Ricky spending most days in the safety of a secluded warehouse, stripping cars for scrap metal, and in a place where he didn't have to socialise.

This isolation left Ricky feeling uncertain about what would happen to him in the future, and made it hard to find employment.

That all changed in early 2020 when a national newspaper article highlighted Ricky's plight and introduced New Zealanders to what it was like to live in silence and isolation. A member of the public approached SCIP and made an anonymous donation, which was put towards Ricky's cochlear implant surgery. Without this generous donation Ricky would still be on the waiting list, potentially with no hope of ever receiving a governmentfunded implant.

Stuff reporter Andrea Vance followed up the initial story, and interviewed Ricky after he received his cochlear implant. He told her, "It works. It works for me so it must work for everyone else that needs an implant. I have still got a bit of a future ahead of me."

Ricky's close friend Sandy Brett said he was a "different man" since his surgery.

"He has so much confidence now. He laughs more, jokes more, and is really enjoying his work. He is just so happy. To me it is a miracle. It really makes you realise how important it is that more people can access this technology."

Our challenges

The work our specially trained team and surgeons do is life-changing. Profound hearing loss is isolating and disheartening. It affects family life, social interaction, the ability to learn and work in what is essentially a hearing world.

NCIP and SCIP want to make cochlear implants and their associated benefits more easily attainable and to better meet the rising level of demand. This includes those we consider most vulnerable.



John Reweti Davis

"I am of Ngā Puhi descent, and I received my cochlear implant in 2015. It changed my life. Life was tough before I received my implant because I had isolated myself from my friends and family. I thought I was useless and had cut myself off from everyone. The implant has resulted in a big improvement in my hearing but the social damage the hearing loss caused will take much longer to recover from."

John Reweti Davis

CONCERN FOR VULNERABLE COMMUNITIES

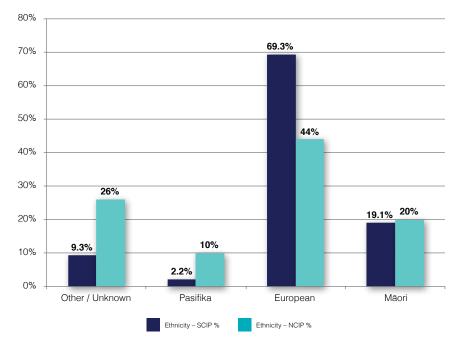
The impact on Māori and Pasifika adults is greater as they are less likely to seek help.

COCHLEAR IMPLANTS – ADULTS

80% 73.9% 68.2% 70% 60% 50% 40% 30% 21.0% 17.8% 20% 11.2% 10% 4.1% 1.0% 2.8% 0% Other / Unknown Pasifika European Māori Ethnicity - NCIP % Ethnicity - SCIP %

THE SAME TREND APPLIES TO CHILDREN

But engagement is higher in children through universal newborn screening, schools, and outreach.



COCHLEAR IMPLANTS – CHILDREN

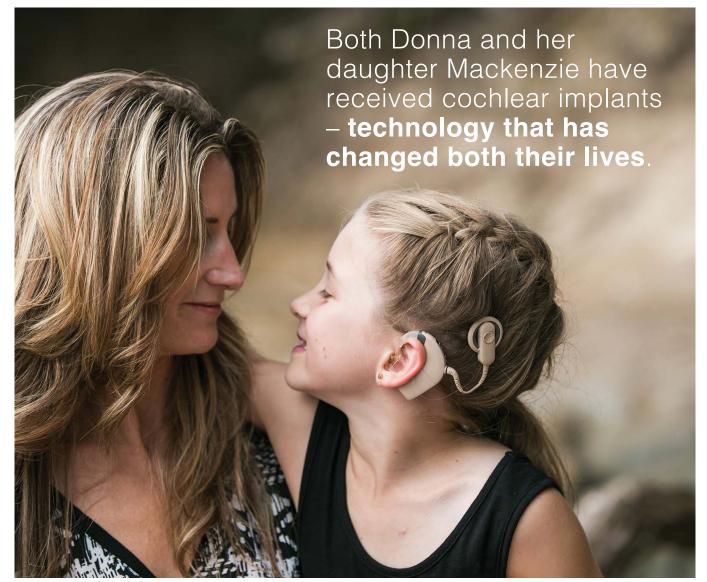
I live in a very small town called Ōkaihau in the Bay of Islands, twenty minutes out of Kerikeri. I work on the farm and my passion is my horses.

The worst part of not hearing was missing out on a lot of conversation.

It was especially embarrassing when I would reply to someone with the wrong answer...I'd totally misunderstood the whole conversation! Socialising was a nightmare and meetings were confusing.

I can hear music, pick up the right conversation, and even talking to strangers is no problem now. It's allowed me to go out socialising and even to join new clubs like roller derby...

> The cochlear implant has changed my life: it's a new world!"



Donna and Mackenzie Quinn.

"I was born with a congenital progressive hearing loss for which I was fitted with bilateral hearing aids when I was two years old. When I reached my early twenties, my hearing progressively got to the point where the hearing aids were of no benefit. A world of silence robbed me of the business I had built up. I could not hear or talk to my customers as well as I used to, answer the phone, take bookings...it was just too hard.

Looking back, I think I was really quite depressed. But then I was given hope. There was light at the end of the tunnel that I could be part of the hearing world again, through the gift of a cochlear implant."

Donna Quinn

We appreciate that there will always be unmet need in a public health system but for adults, as well as children, **cochlear implants completely change lives**. "Thanks to my cochlear implant, I was able to travel halfway around the world studying and doing my OE like so many other Kiwis before me. I now have the ability to choose whatever path I want to take in life."

Lachie Bartlett, Christchurch

For more information or to request an in-person briefing, please contact

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Northern Cochlear Implant Programme

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