SAME FAMILY, DIFFERENT JOURNEYS

Lance Cairns and granddaughter Isabel
On February 1, 2012, the deaf and hearing impaired sector was delighted at the captioning of 13 channels by SKY TV – bouquets to SKY TV!

Brickbats to Parliament for failing to provide Mojo Mathers with the funding she required to ensure she has equity and access at the same level as her hearing able colleagues. The New Zealand government has ratified the United Nations Charter on the Rights of People with Disabilities; now all they need to do is implement it!

This matter is being closely monitored by the Captioning Working Group, a collaboration of NFD, Deaf Aotearoa and the Hearing Association. See page 8 for a report.

On another note, when I was in Adelaide recently, I was stopped by a complete stranger and asked if I was deaf, to which I replied that I had a hearing impairment. She confided that she was about to have a cochlear implant – she was anxious about the procedure and the aftermath and did I know anything about them. I spent time talking with her about the positive difference to her quality of life that a cochlear implant may well offer.

Another significant innovation is that of the FM transmitters and receivers for students, opening the door to educational success for children with Auditory Processing Disorders and other hearing impairments. In the past, such children may well have been slow learners who were disruptive and unhappy.

We talked with Professor Peter Thorne of Auckland University’s School of Population Health, to get an insight into using stem cells and gene therapy, among other advances. See pages 14–16 for a round-up of some promising research.

In November last year I attended the Oticon Foundation’s thought-provoking Spring Hearing Forum at Auckland University. Dr Ofa Dewes, of the School of Population Health, said that the World Health Organisation believes that 50% of hearing impairment, globally, is caused by disease or noise damage – which means it is preventable.

Audiologist Mary O’Keefe then reported on research indicating that untreated hearing impairment in the elderly has causative links to dementia. As the recognition of the impact of hearing loss grows, researchers are asking the hard questions.

On our cover we have world-renowned cricketer (now retired) Lance Cairns and his beautiful granddaughter, Isabel. Both have benefitted from groundbreaking research on cochlear implants. Their stories show how, thanks to research, the life journeys of many who are severely deaf are now vastly different from those who have gone before. Our heartfelt thanks to the Cairns family for their willingness to talk openly about their familial deafness and the way they have grasped the opportunity through cochlear implants to hear again.

Professor Peter Thorne also features on page 19 as our first ‘Hearing Hero’. He is Chair of the NFD Council, and an inspiring and compassionate advocate for the hearing impaired.

By now you will be aware of the extensive advocacy work that goes on every day at The National Foundation for the Deaf. Underscoring this is the firm belief that we, the hearing impaired, are people of true value and worth and that people genuinely want to help and support our sector to achieve and succeed.

All the best

Louise Carroll
Chief Executive Officer
New Board member

Rebecca Davis

Rebecca is an independent consultant, specialising in change and transformation management, community engagement and innovation. She has spent eight years in tertiary education and 12 years in the media.

Her father, an army vet, is now hearing impaired, and so she is learning how whanau can support and adapt.

‘I am passionate about New Zealanders and our communities. I want to make a difference and use whatever skills or talent I have to ensure Kiwis are getting the best opportunities possible.’

Rebecca has a 16-year-old daughter at Rangitoto College who lives with her and her partner, Peter, on the North Shore.

Feedback from our readers

In a recent survey we invited supporters to comment on our magazine.

Hearing Matters is an ideal name for the magazine. The format is well set out and very interesting reading from cover to cover. Well done! You, Louise, and your team are doing a great job.

Anne Franks, Rangiora

I appreciate how hard it is for deaf people. My mother is going deaf. I think you do a very worthwhile job. I was interested to read about cochlear implants.

Mrs Macdonald, Auckland

I am 81 years old – still have good hearing – but have supported you as a worthwhile charity for many years and hope to continue to do so.

Ms Yensen, Napier

I find the magazine interesting and attractive, very well produced.

Dr Glynnis Cropp, Palmerston North

Your newsletter was very interesting and informative. I have used hearing aids for four years although have been aware of hearing loss for about 10. My loss is in high pitch and as a music teacher I have increasingly found young children difficult to hear as well as the fast speech some teenagers use today. Soft tone speech is very frustrating, as are accents on TV. [Hearing] aids have certainly helped.

Mrs Suzanne Raper, Waitara – donor since 1999

We welcome comments from readers. Email us at enquiries@nfd.org.nz or write to PO Box 37729, Parnell, Auckland 1151.
**A first in Parliament**

The National Foundation for the Deaf warmly congratulates the Green Party’s Mojo Mathers on becoming New Zealand’s first profoundly deaf member of Parliament.

The NFD hopes that Ms Mathers’ appointment may help make parliamentary information and debates more accessible for people who are deaf and hearing impaired.

‘She is a shining example of how we can all be positive, active members of our communities,’ said CEO Louise Carroll.

**Here’s to our supporters**

Last month we held our first Hearing Heroes Morning Tea in Parnell. It’s a way to recognise our major gift donors each year. It was also a chance for us to thank people in person for their valuable contributions in 2011, discuss the issues we’re addressing, and share our ideas for the future. Professor Peter Thorne spoke about the face of hearing impairment in 2012.

**Sign up for CapTel**

CapTel (captioned telephony) is now on offer for people who are deaf or have impaired hearing, vision or speech. You read an instant relay of your conversation on a screen, while listening to the actual sounds of your caller speaking. When 200 users have signed up over the next six months, the service will become available throughout New Zealand. Users pay half the cost of the phone ($323 incl. GST), and the government funds the balance. For more information, please call our office on 0800 867 446.

**Screening newborns**

The NFD is now the point of contact for the nationwide service known as Project HIEDI (Hearing Impairment: Early Detection and Intervention). The programme screens new babies for hearing impairment. Policy Manager Dara McNaught will be working one day a week on the project.

**A celebration of survival**

At Christmas, we hosted a ‘You are amazing – thanks a million’ morning tea for about 50 Christchurch volunteers. In the aftermath of the February 2011 earthquake they supported deaf and hearing impaired Cantabrians who became isolated when their hearing equipment was damaged. Since then they have been giving practical help whenever it’s needed, seven days a week.

To show our appreciation for their efforts over so many months, we presented certificates and gifts to Alan Bensley (President, NZ Federation for Deaf Children), Kellye Bensley and Robyn Carter (NFD Captioning Working Group), Paul Botha (Hear for Families, Auditory Processing Disorder support group), Bernadette Collins (hearing therapist, Life Unlimited), John Harwood (President, Hearing Association), Dave Kent (Southern Cochlear Implant Trust), Pauline Marshall and Ivan Taylor (The Hearing Association Christchurch) and Lisa McKenzie (audiometrist).

**Hear for Families**

This month Christchurch saw the launch of Hear for Families, a national organisation that helps families with a member who has Auditory Processing Disorder (APD). APD is a hearing disorder that affects how the brain processes speech, and has been linked to learning difficulties. Chairman Paul Botha said there was a clear need for support: ‘Everyone deserves the right to enjoy quality of life in all its fullness.’ Contact Paul at botha.s.paul@gmail.com/ 027 289 6129.

**Speaking out down south**

In November 2011, Louise Carroll and Dara McNaught of NFD, and John Harwood, President of the Hearing Association, attended the ‘Every Body In’ Disability Studies Conference at Otago University. Presenting ‘The Face of Hearing Impairment in New Zealand’, they spoke on the lack of funding for hearing aids and cochlear implants; the need for captioning of TV and movies; the effects of hearing loss on the elderly; and recent ACC legislation that denies hearing aids to claimants with hearing loss from noise at work.
Captions on SKY

On 1 February SKY TV began offering closed captions on 13 channels, including TV1, 2, 3, Discovery and UKTV. (‘Closed’ means the caption function is turned off; you turn them on via the remote.) ‘This is a huge step in improving access,’ said Louise Carroll. ‘The limited number of captioned television programmes is an ongoing issue. We congratulate SKY TV in taking the lead, and we strongly encourage the other broadcasters to follow suit.’

Help with going digital

For two years NFD has contributed to a disability working group on the Going Digital campaign, about switching from analogue to digital TV. One aim is to ensure that the hearing impaired sector, which includes many elderly people, is being catered for and getting the message. In January the Minister of Broadcasting announced the Targeted Assistance Package for those who face the biggest barriers in going digital. This group includes those who are 75 or over with a community services card, or receiving a veteran’s pension or invalid’s benefit. More on Going Digital, page 7.

Meet the team

We’ve had a few arrivals and departures in the last year. Here’s the current NFD office line-up.

Louise Carroll
Chief Executive Officer
Louise has worked for many years in non-profit, government and corporate trustee organisations, and has represented health consumers at ministry level in Australia and New Zealand. Her 2.5 years at NFD have seen the organisation relocate, restructure and re-establish.

Roxanne de Bruyn
Manager, External Communications
Roxanne has recently joined NFD, bringing experience in marketing and communications in the health and education sectors. She is working on raising awareness of issues that affect the deaf and hearing impaired community.

John Shaw
Manager, Sustainability
John’s experience is in fundraising and communications, most recently for heart research in Australia. His focus is on building a strong income and donor base.

Sara Huszak
Manager, Administration
Sara oversees the day-to-day running of the office. She also contributes her design skills to the Foundation’s brochures and other publications.

Nick King
Assistant Manager, Sustainability
Nick is an experienced fundraiser and direct marketer from the UK. Before joining NFD he worked for four years at Action on Hearing Loss, formerly The Royal National Institute for Deaf People, in London.

Anna Gatland
Administration Assistant
Anna is on our Member Services Team. She is working one day a week while completing Honours in Psychology.

Dara McNaught
Manager, Policy
Dara has many years’ experience in the health and disability sector as a social worker and manager. She has prepared papers on ACC’s changed legislation, and on bullying of people who have hearing impairment.

Erica Siviter
Administration Assistant
The longest standing member of the team, Erica has been with the Foundation for over 17 years. Her work includes processing donations on our supporter database.

Jaspal Kaur
IT and Administration Assistant
A graduate of AUT, Jaspal joined the Foundation in 2011. She is working on the Safe Sound Indicator project, and offers IT skills and technical expertise.

Support us online
Donate securely at www.nfd.org.nz

Your dollar starts working right away, supporting our essential services. You’ll receive an instant receipt by email.
Technology is having a huge impact on the way clinicians diagnose and treat hearing loss. Audiologist, Stephanie Mears, looks at how the latest innovations are changing the way she treats her patients and the huge positive impact it is having on their lives.

“I feel like I have my life back.” James Burns couldn’t believe his ears when he was fitted with new high fidelity, noise reducing hearing aids. Compared to his old clunky beige models, the new hearing aids were light-years more advanced. His old hearing aids would whistle and buzz in his ears making him ‘give up’ on conversations and he’d only take part if he was being directly addressed. With the new hearing aids James can now hear where sounds are coming from, making it easier for him to follow a conversation and join in.

James is just one of hundreds of examples I’m aware of where new audiology technology has made an enormous difference in a patient’s life. In the past five years the leap in technical advancement has been astounding. Hearing devices are now smaller, more discrete and clearer than ever before.

Some of these life-changing advancements include the use of wireless technology, especially Bluetooth. Five years ago Bluetooth was the domain of geeks and computer nerds. Now it’s everywhere – from hands-free car kits to interactive billboards. Hearing aids with Bluetooth can connect directly to external audio devices like a stereo, computer, mp3 player, mobile phone or TV giving outstanding sound quality without competing noise.

More sensitive microphones and advanced sound processing mean a patient can enjoy natural sounding voices and clear, rich, vibrant sound. The addition of special digital anti-feedback systems mean whistling and buzzing hearing aids are definitely things of the past. The latest hearing devices can even filter some types of background noise to reduce distractions and enhance speech clarity. The most recent advances have been in directionality where a pair of synchronised wireless hearing aids can replicate true stereo and better mimic our natural hearing.

This allows a listener to focus their attention in the direction of a voice and makes following a conversation much easier, particularly when there’s a lot of competing noise such as in a restaurant or at a party.

Another way technology is also having a massive impact is in the equipment used by Audiologists to test hearing and accurately programme hearing aids. At Bay Audiology we’re fortunate to have the latest diagnostic testing, and hearing aid fitting and measurement equipment. It allows us to thoroughly diagnose and treat our patient’s hearing problems in a quick and non-invasive way.

It’s well documented that early identification and treatment plays an important role in reducing the negative effects of hearing loss on someone’s life. Bay Audiology makes the testing process easy and convenient for patients, reducing one of the major barriers to better hearing.

When hearing aids are recommended, we use the latest hearing aid measurement systems to make sure we achieve the perfect volume and clarity from the selected hearing devices for each individual patient. This is a critical factor in the satisfaction of hearing aid wearers and the results we see from our happy patients speaks for itself.

It’s these seemingly little things that make a big difference in the lives of our patients. In ongoing follow-up appointments with James Burns, he almost always comments on his previous reluctance to do anything about his hearing. Even after he got his first hearing aids six years ago, James didn’t want to contemplate changing. “I was used to my old ones. It wasn’t until I tried something new that I realised how much I was missing out on.” Multiple microphones, Bluetooth, early and accurate testing – the technology may not be out of this world, but it’s a giant leap forward for anyone experiencing hearing loss.

At Bay Audiology we’re committed to being New Zealand’s best audiology provider by delivering excellent patient care.

• We use the latest diagnostic testing technology.
• We tailor solutions to the patient’s needs, budget and lifestyle.
• Our After Care programme ensures patients receive ongoing treatment.
• We are committed to the hearing impaired community.
• As part of our battery recycling programme, for every kilo of batteries we recycle we donate $1 to the two National Cochlear Implant trusts.
• Every year we supply and fit reconditioned hearing aids to the less privileged in the Pacific Islands.

Stephanie Mears has over 16 years experience as an Audiologist. She has a Masters Degree in Audiology and is a member of the New Zealand Audiology Society. She is currently employed as Bay Audiology’s Clinical Director and still practices as an Audiologist.
Captioning: who pays?
The debate over funding for MP Mojo Mathers has highlighted the wider issue of TV captioning.

Mojo Mathers made history as our first profoundly deaf MP, but she was asked to pay up to $30,000 for electronic note-takers out of her own support budget. At the time of writing, Parliamentary Services could not provide extra funding to aid her in the debating chamber.

We are glad that this issue has become a point of national discussion, as it raises awareness of the barriers that the hearing impaired contend with every day.

We and other concerned organisations and individuals have already pointed out that live TV captioning would enable the deaf and hearing impaired to exercise their democratic right and follow parliamentary proceedings. It would also assist any MPs with hearing problems. It is a matter of equity, as Ms Mathers stated in her maiden speech, that Parliament should be accessible to elected representatives with disabilities.

However, when it comes to ongoing aid for those with disabilities in the workplace, the question of ‘who pays’ is often the most contentious.

We believe it is intrinsically unjust to require an MP with a disability to use their MP support budget to enable full participation while serving their constituents.

In other areas, meetings and events are making use of assistive listening technology for all participants, not just ‘those with hearing impairments’. Sound field systems, for instance, help to make a speaker more audible to everyone in the room, and FM systems can help most people to hear a speaker more clearly.

There is a simple solution to this problem with access for Mojo Mathers. Though she will need captioning support in Select Committee meetings, captioning of the House debates on the Parliament TV channel would provide access for all MPs, and for their constituents nationwide. More on captioning, page 8.

Switching to digital TV

Over 80% of New Zealand homes now have digital TV. Going Digital is the government campaign to get the rest of us ready.

New Zealanders have been watching digital television for several years. Now it’s time to switch off the old analogue transmission system. This will happen progressively across the country, between September this year and November 2013.

There’s plenty of time, but Going Digital is encouraging people to plan now.

Why switch?
As thousands of New Zealanders know, digital TV provides better picture and sound quality and more channels than analogue.

Subtitles are available on selected programmes on Freeview, TelstraClear and SKY. Teletext will also continue.

Freeview and pay-to-view
Freeview is the free-to-air digital TV service, and SKY offers pay-to-view (subscription) services. In Wellington and Christchurch, TelstraClear provides free-to-air and pay-to-view via its cable network.

What you need to do
If you already watch Freeview, TelstraClear or SKY, you are receiving a digital TV signal, so you don’t need to do anything.

If you are not already watching Freeview, TelstraClear or SKY, and you have an older analogue TV, you will need new equipment for your existing TV. For most people that’s a UHF aerial and a set-top box.

You can use a UHF aerial to watch digital TV in most parts of New Zealand. In the few areas where you can’t, you may need a satellite dish and a set-top box.

Check your equipment
Going Digital affects second television sets, video recorders and some DVD recorders. All analogue television-receiving equipment needs to go digital to work effectively. If you often record programmes, you could consider a new personal video recorder, which is designed to work with digital television.

Help and advice
Greg Harford, National Manager for Going Digital, invites National Foundation for the Deaf members wanting more information to contact Going Digital. ‘We have a comprehensive website, so people can get the information and advice they need about switching to digital TV.’

Going Digital also has community advisers who work with local groups and organisations, including the Foundation. ‘We would like to work with NFD to help all New Zealanders understand what they need to do to go digital, and our community advisers are available to meet local groups.You can also ask your retailer about the options.’

www.goingdigital.co.nz
Community advisers: www.goingdigital.co.nz/questions/community-advisors.html
Freephone: 0800 838 000, 8.30 am to 5 pm weekdays.
Callers can access the TTY relay service.
Captions should be compulsory

The volume of captioning on our TV channels is among the lowest in the western world. Australia, the USA and many other countries are required by law to provide captions.

The NFD has set up a working group with Deaf Aotearoa and the National Hearing Association to achieve equal access to TV and movies for deaf and hearing impaired people in New Zealand. A 2011 survey showed that the sector felt a strong sense of injustice and frustration at the way poor TV, home video and cinema captioning denied us the simple pleasures of relaxation, entertainment and access to information and education.

Some captioning on TV1, 2 and 3 is funded by NZ On Air. SKY started captioning on 13 channels on 1 February. But this amounts to a small percentage of total TV hours each week across all channels.

This year we are pushing for legislation to make TV captioning compulsory – a change favoured by 86% of respondents in our survey.

The UN Convention on the Rights of Disabled Persons, ratified by New Zealand, states that all persons with disabilities should be able to enjoy TV, films, theatre and cultural activities in accessible formats.

For further information or to help our campaign, please contact
Louise Carroll: 027 288 2785 or 021 076 6990

Closing credits

Physicist James Jespersen, a co-inventor of closed captioning, died in November 2011. The concept began in the 1970s when the US National Bureau of Standards, where Jespersen later worked, devised a way to display the time on screen. This technology paved the way for closed captioning, and the first captions were previewed on The Mod Squad. Jespersen won an Emmy Award for his work in 1980 and was honoured at the White House.

Know your rights

We have been working with the police and the Law Foundation on a DVD that explains the rights, under the Bill of Rights, of hearing impaired people going through the criminal justice system. If you would like to order a copy please phone us on 0800 867 446.

Packs to MPs

In December, we sent information packs to all members of Parliament, highlighting the issues facing deaf and hearing impaired people in New Zealand. Included were a fact sheet and brochures about the services available. The Foundation will meet with MPs this year to see how we can address some of these issues.

Better for business

We are working with corporate groups to help businesses communicate with their deaf or hearing impaired customers or staff members. Corporate workshops are planned, and yellow counter cards are available for reception or point-of-sale areas. The cards give tips to staff, and to customers with hearing loss. Thanks to funding from the ASB Community Trust and Youthtown, we are distributing these free to organisations in Auckland and Northland.

To enquire about workshops or counter cards, please call us on 09 307 2922.

For further information or to help our campaign, please contact
Louise Carroll: 027 288 2785 or 021 076 6990

Give online
You can now donate securely on our new donation web page at www.nfd.org.nz

Click on the Donate Now button and follow the prompts. Your gift starts working right away, supporting NFD’s essential services.
Are you being served?

A world-leading report has highlighted the challenges facing tourists with hearing loss.

Last year we partnered with the New Zealand Tourism Research Institute at AUT to look at the needs of hearing impaired tourists. Led by Dr Sandra Rhodda, the study is based on surveys conducted nationally (167 responses) and internationally (198). It covers tourism, travel and hospitality in New Zealand.

The report, which is the first of its kind, presents a wealth of valuable information for any group trying to develop accessible tourism, in New Zealand and overseas.

The findings revealed a range of needs and issues, including:

- staff with a ‘can-do’ attitude and an understanding of hearing loss
- safety information in clear print
- public announcements in text on TV screens
- a reliable website on tourism businesses catering for the sector.

View the full report at: www.nfd.org.nz

Of the survey respondents, the vast majority in New Zealand (90%) and 55% overseas felt that the service for people with hearing loss needs to improve.

Thumbs up for the tick

The NFD aims to create a ‘Hearing Tick’ system for businesses that cater for people with hearing loss – similar to the Heart Foundation’s ‘Healthy Heart Tick’ used on food products. The majority of those surveyed agreed that a hearing-rated symbol was a good idea.

Grants received by The National Foundation for the Deaf in 2011

We gratefully acknowledge funding from the following agencies:

AK Franks Trust
ASB Community Trust
Charles Rupert Stead Trust
Department of Internal Affairs – Community Organisation Grants Scheme (COGS)
Estate of George Sevicke Jones
Four Winds Foundation
JA Redwood Charitable Trust
Joyce Fisher Charitable Trust
The Law Foundation
Mana Community Grants Foundation
Maurice Paykel Charitable Trust
New Zealand Community Trust
New Zealand Lottery Grants Board – Lottery Minister’s Discretionary Fund
New Zealand Lottery Grants Board – Lottery National Community Committee
N R Thomson Charitable Trust
Oticon Foundation
Pelorus Trust
Pub Charity
SKYCITY Auckland Community Trust
The Trusts Charitable Foundation
Todd Foundation
Trust Waikato
Youthtown Trust

Keeping the decibels down

Over 1000 preschools now have a Safe Sound Indicator (SSI). Recently, primary schools have begun to recognise their value, too.

We’ve written before about our SSIs, which are a great way of encouraging our children to play and learn without damaging their hearing. And many of our supporters have commented on what a good idea they are.

In 2012 we want even more children to have access to SSIs. Hearing protection at a young age is vital if we’re to avoid a hearing crisis.

Children at Torbay School learn about the ‘traffic light’ box. It flashes green, amber or red as classroom sound levels increase to 90 decibels – loud enough to harm hearing.
Hearing Week: 25–31 March 2012

Hearing impairment is invisible … and it’s all around us. It affects 1 in 6 people – that’s over 700,000 New Zealanders.

Once again Hearing Week will focus on the diverse faces of hearing impairment, ranging from a toddler to a senior. Some have hearing aids, others have cochlear implants. We want to raise awareness within the community that hearing problems can affect anyone, at any age. The aim is also to show those who live with hearing loss that they are not alone.

This week is also an opportunity for groups working in this sector to profile the work they are doing. See what our member groups are up to: www.nfd.org.nz

Technology brings hope

This year we’re showing decision-makers why it’s so important to give people access to technology. More sophisticated hearing aids, FM systems and cochlear implants have already transformed life for thousands of New Zealanders. Rapid progress is being made on smarter devices, gene cell therapy and other solutions. For promising research, see pages 14–16.

The faces of hearing impairment

These six amazing people will feature in a television commercial that will be aired across the country. You’ll find video clips on the NFD website at www.nfd.org.nz

Dylan Vaughan
Born profoundly deaf, Dylan (2) is progressing well after receiving a cochlear implant at 16 months. See back page for more.

Rachael Morris
Rachael has hereditary hearing loss. Until last year she wore two hearing aids, and eventually had to give up work. But since her cochlear implant five months ago, she’s experienced a huge improvement in her quality of life.

Sama Yaghi
Although Sama has a hereditary condition, it wasn’t picked up until she was two. Hearing aids were trialled, and then she received an implant when she was three. Now six, Sama is chatty and speaks with clarity and confidence at school.

John Harwood
John has been a farmer, builder, painter and landscaper, and he volunteers for five organisations including the Hearing Association. His hearing loss, now at 85%, stems from army training in the 1950s, and noisy machinery. He has two hearing aids.

Jemma Dorward
Hearing impaired from birth, Jemma (13) wears aids in both ears. Noisy classrooms are no problem: ‘It doesn’t feel like I’ve got hearing aids.’ But she would love to have waterproof aids for swimming.

Jemma Webb
Jemma (also 13) was born profoundly deaf and got a cochlear implant at age two. At 10, she received a second implant. ‘It made a big difference – I can hear things louder, and now I know which direction sounds are coming from.’

‘Life without hearing aids would be a corner of a room with no communication.’
– John Harwood
Leaving a bequest

Mt Albert resident and NFD supporter
Sean McKillop has good hearing, but he’s seen for himself what obstacles hearing loss can cause.

‘Everything is done for a hearing world,’ he says. ‘You can’t hear cars and vehicles. A lack of hearing leads to a lack of communication. It’s even felt when you go to the shops – you can write things down and try to lip-read, but if the person turns away... it’s very hard.’

He’s been a Lion’s Club member for decades: ‘They’ve done a lot for deaf people and I’ve been involved, for example during Deaf Awareness Week.’

He decided to include NFD in his Will because he knows that the Foundation will be a good custodian of his money. ‘I want to make things easier for others less fortunate after I go. I also know that it’s going to be kept in New Zealand. I want that money to be used to enlighten and educate people about what hearing loss means, and how lucky people are to have their hearing, so they value it more.’

Bequests allow us to have an impact after we’re gone – to become role models for future generations, and continue to be a force for good. They’re also a way of making a significant gift that doesn’t affect our day-to-day finances.

A bequest is a provision in a Will for a gift – a sum of money, property, shares etc – to a charitable cause such as NFD. Those who already have a Will can add instructions in a codicil (an appendix).

A Will and a codicil must be worded and witnessed correctly to be legally binding, so you should always consult a lawyer or financial advisor.

Making a bequest is one of the most valuable contributions you can make to our work. If you wish to discuss this in confidence please call John Shaw, Sustainability Manager on 0800 867 446 or email john.shaw@nfd.org.nz

Sean McKillop: ‘By leaving money to NFD, I know it will be spent wisely and put to good use.’

NFD Hearing Week activities

- Posters, TV and radio: the six faces of hearing impairment. Each has a story – see www.nfd.org.nz
- Campaigns on Facebook and Twitter.
- Information packs sent to MPs and media, highlighting the top three issues in our sector: TV captioning, funding hearing aids/PM and funding cochlear implants.
- A video is also being sent to MPs, featuring claimants voicing their concerns about ACC’s unrealistic thresholds for injury-related hearing loss. It shows how someone with noise-induced hearing injury was successfully rehabilitated, compared to the current situation where they are being denied funding for treatment.
- Bullying prevention workshops.

Support our work

You can donate at any branch of ASB Bank during Hearing Week. Make an instant $20 donation: please call 0900 666 20.

Donate online: www.nfd.org.nz

Bullying prevention workshops

It is recognised that people with disabilities are more at risk of being bullied. To raise awareness of this issue, workshops are being held in Auckland, Wellington and Christchurch during Hearing Week.

Designed for those working in health and domestic violence recovery, the sessions are being co-ordinated by Dara McNaught, NFD Manager of Policy. The facilitator is New Zealander Hadyn Olsen, an internationally recognised expert. The workshops will include:

- Best practice communication with a person with hearing impairment
- Examples of bullying the hearing impaired
- A DVD discussion with a hearing impaired woman who has been bullied
- What you can do.

For more on Hadyn’s work, see www.wave.org.nz

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A world of difference

Cricket legend Lance Cairns and granddaughter Isabel both have cochlear implants. Their stories trace the advances in treatment for hearing loss.

The dazzling sportsman took 130 wickets in his 43 tests, yet for decades he struggled with other challenges off the field.

Lance didn’t use hearing aids until his 30s, and he was 60 when he first learned about cochlear implants. In contrast, Isabel (daughter of Lance’s son Chris, a former Black Cap), received an implant at five months, and monitoring continues as she grows up. Thanks to early intervention and evolving technology, she won’t miss a beat.

Second innings

Lance Cairns talks of life before and after an implant.

I left school at 15 and worked at the freezing works. It was noisy, working without headphones where they washed the carcasses with an air-pressure hose.

By 18 I was experiencing hearing loss, and my mother noticed that she had to repeat herself when talking to me. I was a big rock and roll fan, but I couldn’t get the beat and I lost all interest in music. I was diagnosed with a hearing problem, but I didn’t get hearing aids and by age 23 I was playing cricket for New Zealand full time. So all the talk was about cricket, and I only needed to hear bits to pick it up. When we had a team meeting, Jeremy Coney [see box] would take me aside and tell me what was discussed.

I didn’t talk about it, but I didn’t want to go out or mix with people. It wasn’t until after I finished cricket, when I was about 37, that I went to see someone about a hearing aid. Because I was a familiar face, the Sonac clinic offered me two hearing aids if I did some work for them.

That period from my 30s to almost 60 was tough – hearing aids are not perfect. It was just amplified noise. My hearing was getting worse all the time, and I was lucky that people knew who I was. Finding work would have been much harder otherwise.

‘Listening and learning all over again’

Then somebody mentioned cochlear implants. I hadn’t known about them, because your hearing loss has to be so bad before you’re eligible. At 60 I was assessed as suitable. Fortunately an Australian cochlear expert, who was a cricket fan, gave my audiologist a cochlear implant for me. Otherwise, I’d still be on the waiting list.

Unless you’ve suffered, it’s hard to understand what the difference is: to go into a room of people and follow the conversation; not to be afraid to go to a function, or talk on the phone.

What brought it home was the 2011 Grocery Charity Ball [held for the Hearing House], where two kids with cochlear implants spoke. One was about nine, and the other was at university. The audience realised that these things are so great and good, and it made them sit up and take notice.
Head start

Soon after Isabel was born, in Australia, a compulsory hospital hearing test picked up a possible problem and she was referred to a paediatric audiologist.

After about five hours of testing, her parents Mel and Chris Cairns learned that their very vocal baby had a severe to profound hearing loss. ‘We had no idea what that meant, but essentially she had very little hearing,’ said Mel. ‘It was a huge shock.’

Because her hearing loss was so severe, Isabel was a potential candidate for cochlear implants. Babies are known to babble until six months, but after that, if they are not hearing themselves they tend to stop. So for Mel and Chris it was important that Isabel got her implants before this point.

The timing was good: her grandfather had recently received an implant himself. ‘It would have been a lot scarier if we hadn’t had that experience with Lance. We’d seen how much it had changed his life.’

At nine months, Isabel is chatting and starting to crawl. She has full access to sound and is hitting all her developmental milestones. As she grows, her ‘sound map’ will change and she’ll continue to be monitored. She attends the Shepherd Centre in Canberra where audiologists and speech pathologists help to prepare her for school.

‘I’ve been told the next frontier is to give lessons to remote children over Skype,’ says Mel. ‘This is very exciting. The technology just keeps getting better, and the implants are getting even smaller. It will be amazing to see her in 10 years’ time.’

Cochlear implants: what’s next?

Around the world, researchers are looking to enhance the benefits of implants.

A cochlear implant consists of two main parts. The external speech processor sends signals to the implant beneath the skin and its electrodes which are in the cochlea of the inner ear. These electrodes activate the hearing nerve in the cochlea, bypassing the damaged sensory cells of the inner ear, and giving a sense of sound.

A major push is in implanting bilateral implants – using both ears. You get a better orientation to sound, and you can hear in different environments. There’s also an increasing focus on developing implants for other parts of the auditory system, such as the brain stem and cortex. Different areas of the brain important for hearing can be stimulated in this way, if the hearing nerve is damaged.

Future devices may not be as obtrusive. At the Massachusetts Institute of Technology scientists are working on a fully implantable device. It will process more impulses faster than current devices, and the battery will only need recharging every two weeks.

Nanotechnology (studying systems at the molecular level) could make implants much more effective. The ear has 30,000 nerve fibres, yet a cochlear implant uses only 22 electrodes, each one stimulating a bundle of nerve fibres. The goal is to increase the electrodes, and make them smaller.

At Cincinnati Children’s Hospital they’re looking at synthetic polymers that can convert sound energy into electrical impulses. These new materials would eliminate the need for hardware and a power source, and reduce the extent of surgery.

Two for one

People with less than a profound loss can also benefit from implant technology. Hybrid aids have been developed to exploit any hearing that is still available. These connect to both the damaged area (with an implant) and the healthy part of the ear (with a hearing aid).
Research round-up

Searching for solutions

The hard of hearing can take heart that experts are on the path to promising developments – whether it’s smarter devices, gene therapy or a deeper understanding of how the ear works.

Hearing loss can affect anyone at any age. Problems range from congenital impairments, which are often genetic, to progressive loss as we get older. The World Health Organisation predicts that by 2030 adult-onset hearing loss will be in the top 10 disease burdens in high and middle-income countries, above cataracts and diabetes.

Today technology and hearing science are advancing together, to capture more natural hearing, and to repair and prevent hearing loss.

Hearing loss in New Zealand costs the economy about $1.8 billion per year. Projections from the United States and Australia indicate that one in four people will have a hearing loss by 2050.

Easing the social and personal burden is not simple. Currently, there is no way to prevent age-related hearing loss, to stop tinnitus, or to restore natural hearing.

‘We’d like solutions at all levels – local and international, community and population, diagnosis and drug treatment,’ says Professor Peter Thorne of Auckland University’s School of Population Health. ‘Knowing what causes hearing loss involves basic science through to clinical application. It’s all interconnected.’
Hearing aids and cochlear implants

In a quiet setting where the sound source is close, hearing aids and implants generally work well. But when it’s noisy or the sound is further away, people find it harder to focus and understand.

‘Much research is on enhancing the interface between the device and the ear, to make hearing more natural,’ says Professor Thorne.

Also on the horizon are ‘self-learning’ hearing aids which, like a computer, can remember and store your preferences for volume and other settings. Hearing aids will be able to link to the internet, so users can connect remotely with their audiologist. See page 13 for the latest on cochlear implants.

Saving the auditory nerve

Researchers are studying how to keep the auditory nerve healthy or to replace a damaged nerve, so it can still process sound or receive an implant. If the inner ear has cells that are available, scientists can take advantage of the natural processes. One approach is to introduce chemicals into the ear, to stimulate the nerve cells.

Gene therapy

In all animals except mammals, an auditory hair cell can repair or replace itself. But because our ears evolved to hear higher pitched sounds, the cells are complex and cannot divide.

Can we replace or repair sensory hair cells, and restore natural hearing? One idea is to turn on the dormant ‘repairing’ gene in supporting cells. Another is to take stem cells that have been forced to make nerve cells and put them into the ear. The challenge is to tap into the natural process that takes the cells to their target, where they would keep dividing.

Identifying which genes are missing, mutated or working poorly will also have a big impact on gene therapies.

Clues from ‘temporary’ damage

Often after exposure to loud noise we lose some hearing, but then appear to recover when assessed with conventional tests. But recent findings suggest that even apparently short-term damage could lead to gradual changes in the ear, ultimately resulting in hearing loss later in life.

This slow or delayed damage affects the connection between the sensory hair cells and the hearing nerves which send information about sound to the brain.

Dr Lukas Rüttiger, at the University of Tübingen in Germany, is studying a pathway that may play a part in this damage. Influencing this pathway may prevent the damage in certain situations. The team will investigate which treatments show promise, and the optimal time to intervene, to prevent damage.

Source: Action on Hearing Loss

Hearing aids may maintain brain function

Researchers at the University of Pennsylvania have found a possible link between hearing ability and brain volume. Compared to those with normal hearing, in people with hearing loss the density of the auditory areas of the brain was lower. This means they have to work harder to understand complex sentences. Lead author Jonathan Peelle said that hearing aids should be considered not only to improve hearing, but also to keep the brain working normally.

‘Preserving your hearing doesn’t only protect your ears, but also helps your brain perform at its best.’

Source: www.hear-it.org

At universities and institutes around the world, hearing scientists are looking for breakthroughs. Research hubs in Australasia include Melbourne’s Bionic Institute, and Auckland, Massey, Canterbury and Otago universities.
Research round-up

Continued from page 15

Understanding the ear
How does the ear work? What goes on inside it? Not all research is about cures. Many answers depend on being able to study this ‘sealed vessel’. Locked away deep in the skull, the ear still holds secrets. Scientists are pushing the limits of technology, using non-invasive methods such as MRI and CAT scans to expand their knowledge.

Pathways in the brain
The auditory pathways take up a lot of ‘brain space’, processing different parts of the sound signal. ‘Our hearing system is a sophisticated computer that connects us with our world, giving us 3D surround-sound, and probing the environment,’ says Professor Thorne. It can also give warning signals, and help you focus on the right sound.

This ability develops in childhood, but some children can’t process sound well – which can affect learning. Professor Suzanne Purdy, Head of Speech Science at Auckland University, is using behavioural tools to retrain the brains of these children to process sound better.

A magic bullet?
Dr Srdjan Vlajkovic at the University of Auckland has tested a drug that could be a first in treating noise-induced hearing loss. It activates the body’s ability to produce protective antioxidants. When given for five days, starting six hours after exposure to noise, it has been shown to prevent up to 50% of otherwise permanent hearing loss.

Phantom sounds
Ringing, hissing, buzzing, clicking, humming – that’s how people describe the perception of sound known as tinnitus.

Led by Dr Grant Searchfield, a team at the University of Auckland has won international recognition for its work on ways to defeat this insidious internal noise.

‘Our hope is to develop effective treatments that are accessible to everyone,’ said Dr Searchfield. These include attention training, non-invasive brain stimulation and hearing aids. Although injury to the ear is thought to be a trigger for tinnitus, it is widely believed that the auditory brain is involved. ‘Damage to the ear creates “holes” which the brain tries to fill in with information, creating a false image of sound.’

If you’re interested in contributing to tinnitus research, please email g.searchfield@auckland.ac.nz

Pioneering projects
The UK’s Action on Hearing Loss is funding four new studies to combat hearing loss.

University of Washington
Topic: A molecular signalling pathway important for inner ear development.
Aim: Help to regenerate parts of the inner ear.

Harvard Medical School
Topic: Regrowing auditory neurons, which transmit signals from the ear to the brain.
Aim: Refine approaches such as gene therapy, stem cells.

University of Leicester
Topic: Restoring hearing after brain damage from jaundice.
Aim: Develop new treatments for hearing loss caused by brain injuries.

Cincinnati Children’s Hospital
Topic: The link between genes that might cause or prevent congenital hearing loss.
Aim: Better understanding of inner ear processes.
Auckland film-maker Brent Macpherson had always wanted to make a documentary about deaf Aborigines, but it was difficult to make contact in Australia’s outback. So when he heard about a remote centre for the deaf in the Solomon Islands, it seemed too good a chance to miss.

The name Solomon Islands conjures up idyllic images – white sandy beaches, blue skies, coconut palms lining the shore. Yet for many living there, it is certainly no paradise. The reality is that the country is very poor, and for the disabled it is hard to eke out a living. With no government support, they rely on international aid for education, health and other resources.

It is known that a high proportion of the population are profoundly or totally deaf. But there are few statistics about the deaf on these islands, many of which are very isolated. There are no known programmes to help prevent further deafness.

An equal education

Started in 2007 by Brother George, the San Isidro Care Centre at Takwa village, outside Honiara, educates the deaf and disabled from the age of about 14. Denied training elsewhere because of their disabilities, they can study courses here over four years – including English, maths, business, sign language, agriculture, life skills and carpentry.

The centre also advocates for basic human rights for the disabled. The vision is to change social attitudes, allowing these people the same dignity and right to a decent living as others. The courses ensure they can become co-developers in society, rather than being marginalised and neglected.

Today there are three permanent staff houses, one industrial workshop and two girls’ dormitories.

Making contact

Brent has made two trips to learn about the culture, and hopes to gain their trust before filming the documentary. ‘I made a 10-hour ferry trip sleeping next to four pigs, and then a 10-hour drive from Auki to Takwa with a group of deaf people. A mind-blowing experience!’

From a school to a community

Brent believes the centre will eventually become a deaf community, as there are now six ex-students based there permanently. ‘Many will choose to stay, simply because of the ease of communicating compared to their own villages.’ Some arrive with no language at all, after years of not being able to hear in their own isolated communities. In many cases, it is too late. ‘It’s so important to have access to education when they are young.’

Raising awareness

Through the project Brent aims to highlight the challenges at the centre. Right now, they need more dormitories, especially for boys, a proper kitchen or dining hall, a chapel, better equipped classrooms and a school bus. They also need trained teachers of the deaf, and qualified interpreters.

Funds are needed for a second-hand school bus. These villagers, all deaf, are crammed into the small truck that carries them long distances over pot-holed roads.

Brent, who is director at Stretch Productions, intends to shoot the documentary in May–June 2012. He needs to fundraise for the project to go ahead. All proceeds from the sale of the documentary and DVDs will go to the San Isidro Centre. NFD supports this vital project. For more information, text 027 721 9918 or email brent.macpherson@stretchproductions.co.nz

About 60 deaf and hearing impaired students (aged between 12 and 35) live in the village, and attend school where they learn practical skills. Compared to what is available to similar students in New Zealand, they have many needs. The project will provide school resources and funding to finish off the huts where they sleep.
Noise at work and play

For Bill Allison, one of thousands of New Zealanders diagnosed with noise-induced hearing loss, years of industrial clamour and guitar playing have taken their toll.

‘Once I had admitted it, I looked back and realised it had been there for a while.’

On the job ...

He believes a lot of the damage happened in power stations and heavy construction sites around New Zealand and Australia. ‘In those days no one thought to use hearing protection. We weren’t informed, and didn’t appreciate the full impact of industrial noise.’

Bill now feels the impact on a daily basis. Although one-to-one conversation is fine, in a group he tends to lose track of what people are saying. ‘I can hear sound, but I can’t always distinguish speech. I’m always turning the TV up.’

Dr Stuart McLaren, Senior Lecturer in Health Sciences at Massey University, says that noise-induced hearing loss is the consequence of prolonged exposure. ‘The continuous noise damages the little hairs on the cochlea and along the audial nerve pathway. This makes processing noise and identifying speech very difficult.’

Bill, now semi-retired and running a small computer business, says his hearing loss does affect his work. ‘It’s annoying – I often find it difficult to hear the authenticity codes when I’m helping someone. I have trouble distinguishing between the soft sounds.’

… and after hours

While he believes that workplace conditions are better, Bill is aware that recreational noise is still an issue. From his teenage years through to his thirties, he played in bands. ‘When I think of the volume we used to play at, it’s a wonder I can hear at all!’ He played six-string guitar and keyboards, but mostly bass. ‘It got very loud, but we just didn’t think about it. Loud music is still a risk today. You don’t see bands on stage wearing hearing protection, do you?’

Dr McLaren notes: ‘The international criteria are built on giving your ears a rest. If you work in a noisy environment by day and then go out clubbing at night, it is very easy to surpass the recommended limits.’

How loud is too loud?

Prolonged exposure to sounds above 85 decibels (dB) may cause permanent hearing loss.

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<thead>
<tr>
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<tr>
<td>140</td>
<td>Shotgun blast</td>
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<tr>
<td>130</td>
<td>Jet taking off</td>
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<tr>
<td>110</td>
<td>Rock group, trail bike</td>
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<td>95</td>
<td>Lawnmower</td>
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<td>90</td>
<td>Heavy truck</td>
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<tr>
<td>70</td>
<td>Noisy office</td>
</tr>
<tr>
<td>60</td>
<td>Normal speech</td>
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Cover up

- Earmuffs protect all parts of the ear, they give the best protection, and you don’t have to keep adjusting them.
- Ear plugs are effective for less intense noise levels. They must be carefully fitted and periodically checked.
- Most do-it-yourself protectors (such as cotton wool) don’t really dampen noise. They fit badly and aren’t hygienic.
A belief that crosses boundaries

Scientist, leader, educator, negotiator, fundraiser – whichever role Peter Thorne plays, it’s with the same purpose: to improve life for those with hearing impairment.

When Peter Thorne began his career, hearing science in New Zealand did not have the status it does today. But through his passion and academic rigour, he has built up its credibility.

Originally employed as the first researcher for the Deafness Research Foundation, Peter is recognised internationally as an innovator. His research has spanned basic science to clinical and population health, and has been published in leading journals. This work has led to significant advances in our understanding of how the ear works, for instance in response to noise stress and aging.

Auckland University’s School of Population Health now has a highly regarded audiology department, where he is Professor. He has inspired many students to pursue audiology as a career and to participate in community initiatives.

‘His commitment to the hearing impaired community is core to his drive in research, and is a philosophy that he instils in his students. He is far more than just an excellent scientist,’ said Grant Searchfield, Head of Audiology.

In the community he has also made his mark, volunteering his skills and thousands of hours. When the detection of hearing problems in children was deteriorating, Peter was a vital campaigner for nationwide newborn screening. His evidence-based report was used to convince the government to take action, and he helped raise over $250,000 for the project. Part-funded by the NFD, Project HIEDI (Hearing Impairment: Early Detection and Intervention) began in 2007. Since then, over 100,000 babies have been screened, and the outlook for many has been transformed.

Peter Thorne has been crucial to the Foundation’s success.

Peter has been closely involved in the governance of The National Foundation for the Deaf for over 20 years, truly believing in its worth and leading it through many changes.

As Council Chair he drove the establishment of the NFD Trust, which funds initiatives in the sector. Colleagues talk of his outstanding ability as a facilitator, keeping diverse groups on course. ‘He’s leading our strategic plan through to 2020, with all the members working together,’ said CEO Louise Carroll.

Peter’s current research is on noise-induced hearing loss, and he continues his voluntary work. He and his wife Rosemary enjoy spending time on Waiheke, where they own a property, but as she comments, ‘Retirement is not on the agenda.’

In 2009 he was awarded the CNZM for services to auditory neuroscience.

Enjoying your meal?

Next time you’re eating out, take note of the sound as well as the flavours.

The Acoustical Society of New Zealand encourages people to rate their dining experience on www.acoustics.ac.nz

Answer seven simple questions about how the noise affected your experience. The society comes up with a 1–5 star rating based on the criteria shown at left, and adds the restaurant to their growing list.

For more information, contact The National Foundation for the Deaf:

Sara Huszak
Ph: 0800 867 446  E: sara@nfd.org.nz

If you’re looking for a pleasant, quiet space to eat, try one of the eateries that rated 5 stars:

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<th>Restaurant</th>
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<td>Charlee’s</td>
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Catching up fast

Two-year-old Dylan Vaughan missed out on newborn screening for hearing impairment. A vocal, inquisitive baby, he was not diagnosed as profoundly deaf until he was 16 months old.

In June last year he received a cochlear implant in his left ear, and his mother Jo says he’s progressing well – repeating sounds, turning round to his name, understanding basic instructions. ‘He’s less frustrated, calmer and easier to manage now he can hear.’

The family recently rehomed Ella, a hearing dog. ‘She didn’t quite make it as a trained dog, but we hope she will help encourage Dylan’s speech and confidence.’

Jo and her husband Neil emigrated five years ago from the UK. They want to give their son the best possible access to sound, so are now raising funds for a second implant – ideally before he turns three in December.

Hearing Matters reaches a broad cross-section of New Zealand’s deaf and hearing impaired community – over 700,000 people.

To discuss sponsorship and advertising, please contact:
John Shaw, Manager, Sustainability
Ph: 0800 867 446
E: john.shaw@nfd.org.nz

Hands across the water

Over 1000 years ago, 14 Polynesian mariners made an epic journey in Malolo, a double-hulled canoe. As they sailed into the unknown, they used their various skills to survive. Author Robert Bonville has used the story for an historical novel, Voyages of Malolo. One intriguing character is Aka’lua, a hearing impaired man. His ability in ‘hand talking’ proves vital, enabling the crew to communicate with people in strange lands during the 27,000-kilometre voyage.

See www.nfd.org.nz/?t=13

Cheap, simple aids

Businessman Howard Weinstein started Solar Ear when he saw the need for an affordable, user-friendly and ecological hearing aid. Designed for people in developing countries, the device has rechargeable batteries and a solar charger. It costs under $100, and patients can be fitted in one visit. Based in Brazil, Solar Ear hires deaf workers throughout the world to invent, develop and assemble its products. Weinstein was named social entrepreneur for 2011 by World Technology Network.

Splashproof

Hearing impaired people can now wear a waterproof hearing aid while they swim, shower and splash around. The Siemens Aquaris can be submerged in water up to one metre, and can also help overcome a common problem linked to hearing aids – humidity and sweat. The housing and battery door are completely sealed to make sure no moisture gets in, and a membrane gives extra protection. The Aquaris is on sale through hearing clinics across the country.

Advertisers: support our magazine

To read about Dylan’s progress or donate, visit: www.dylansmagicear.com

Hearing retest

Last month more than 1300 children were recalled to Dunedin Hospital’s audiology department, after concerns about testing procedures. The children had been seen between 2007 and 2010, but a review had since revealed gaps that could mean a child’s hearing problem was not picked up. The review coincided with a complaint from a parent concerned about the potential for their child being missed. The notified families, including those in rural areas, were required to bring their children back for further assessment.

In 2010 NFD worked with the Health and Disability Commissioner to enable those using this DHB’s audiological services to air their concerns. It is excellent to see this process has continued, and we have heard that the service has been redesigned and is now meeting client needs.