

StrongVoices

EMPOWERED LIVES



Spring 2021

**Colin hangs up
his broom**

**Timing is everything
A town that says yes**



Kōrero

It's interesting to think now and then about the idea that the next generations will grow up to do jobs and have experiences we haven't even thought of yet.

This edition of *Strong Voices* contains some great examples of young people breaking barriers, challenging stereotypes and cutting their own paths in the world.

Katrina Sneath has Down syndrome and is on her OE in Sydney. She has just completed two years at uni 2 beyond at the University of Sydney and is now working at Australia's first social enterprise hotel that trains and employs staff with intellectual disabilities.

Poppy has recently hit New Zealand cinema screens. The film stars Libby Hunsdale, an actor with Down syndrome, and this edition contains reviews from two other young women with Down syndrome who talk about the impact of the film on them.

Tayla Slood has just published a book, *My Life with Cerebral Palsy*, which she wrote and illustrated, and Jeremy Hill-Hayer is getting fit and becoming more independent thanks to a special programme of support being developed by IDEA Services and Choices NZ.

These are fantastic achievements and it's our pleasure to highlight what tenacious individuals can achieve and to give people the opportunity to tell their stories.

But for most of us, success comes with great support and opportunities – from friends, family and our communities – and it builds on what we've learnt as children and young adults at school.

That is why IHC is determined that every child is welcomed at their local school and given the same support and opportunities. This fight is finally heading to the Human Rights Review Tribunal, and parents and carers are helping to update the evidence by talking about their experiences with education in hui around the country.

And let's face it – a lot of what young people learn outside the classrooms is from friends and online. We're delighted to have partnered with InGame on the development of an online game app all about managing money and making choices. There's still some way to go but testing has shown lots of enthusiasm already for *Stand Tall*. Have a read and watch this space.

Ngā mihi
Gina Rogers
Editor

CONTENTS

- Page 3 Money app makes paying bills fun
- Page 4 Atawhai Nursery helps to rescue rare pōhutukawa
- Page 6 Rhonda and Rex hit the road to spread the word
- Page 7 Timing is everything
- Page 8 Colin hangs up his broom
- Page 10 The town that says yes
- Page 12 Families self-isolate for survival
- Page 13 Banks continue their disappearing act
- Page 14 Jeremy's life choices open up
- Page 15 Michael honoured for a lifetime of sporting achievement
- Page 16 Human rights experts hear from parents
- Page 17 Young artists seize their chance
- Page 18 *Poppy* inspires young movie-goers
- Page 19 Tayla shares her awesome life



KEEP UP WITH WHAT IHC IS DOING – FOLLOW OUR CAMPAIGNS AND BE THE FIRST TO READ OUR STORIES AND SEE OUR VIDEOS.

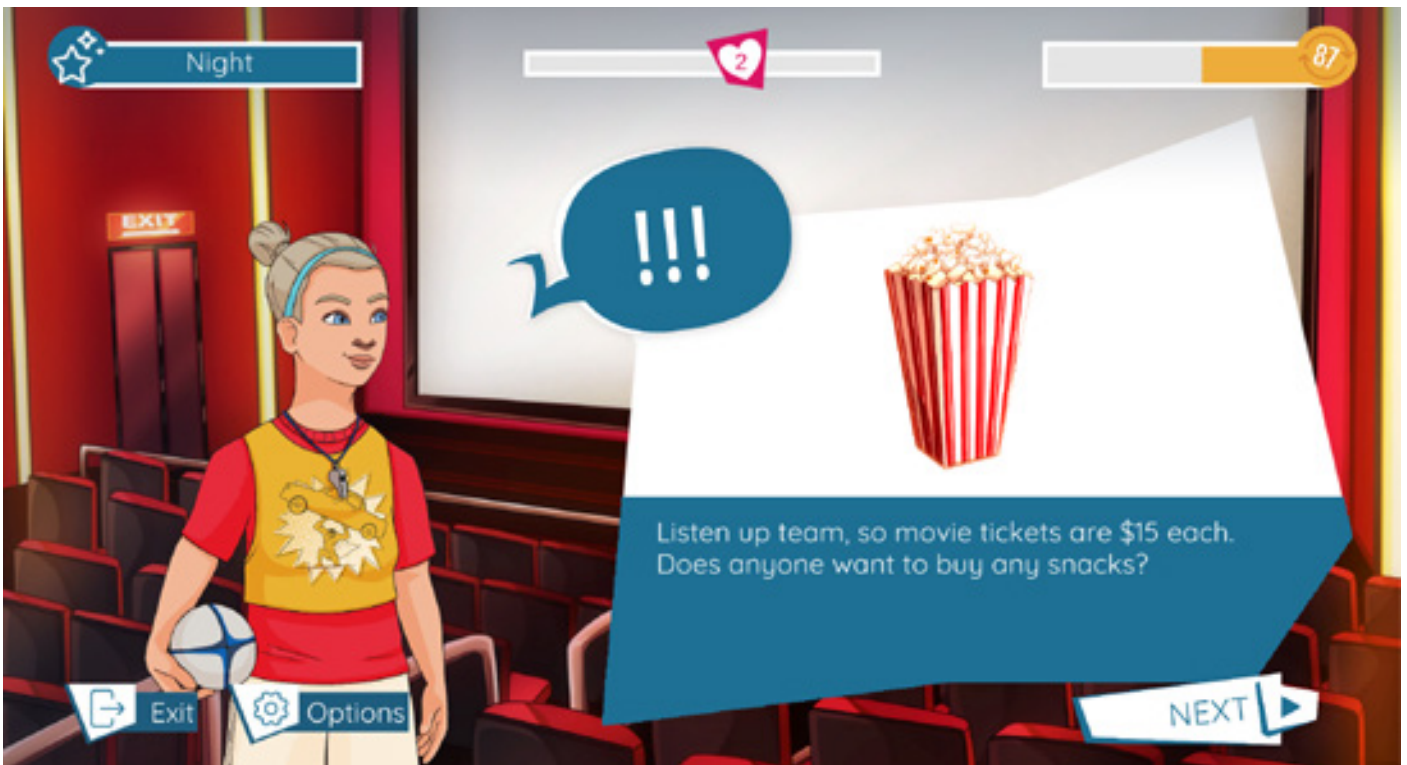
WE'LL KEEP YOU POSTED WITH NEWS AND VIEWS ACROSS THE IHC GROUP AND THE DISABILITY SECTOR.

WE'D LOVE TO HEAR FROM YOU.

**SO JOIN THE CONVERSATION.
FACEBOOK.COM/IHCNEWZEALAND
READ THE STRONG VOICES BLOG
IHC.ORG.NZ/STRONG-VOICES**

COVER IMAGE:

When Colin Bailey retired after 30 years with Hirepool in Lower Hutt, staff came from all over the Wellington area to say goodbye. See the story on Page 8.



VOICES

Money app makes paying bills fun

Stand Tall is a new app designed to dodge those tricky money situations – like getting to the end of the week and finding there’s no cash left for dinner.

The app is being developed by IHC and online gaming company InGame to make handling money easier for young people with disabilities who want to be independent.

“It’s a character-based game, so you choose your avatar – what you’re going to look like in the game,” says Phil Clarke, IHC Head of Library and Information Resourcing. “The background changes as you make decisions in the game and move around your flat and out to the gym or the movie theatre. As you move through the day there are various choices that have to be made.”

Phil says other characters or situations crop up that challenge what players plan to do and how they plan to spend their money.

Another key aspect of the game is shopping, particularly grocery shopping. Players are asked to decide what they’re going to eat.

Phil says each purchase has a consequence and players can see their available money dropping as they spend. But the consequences are not just monetary. The game has two bars for measuring progress – money and wellbeing. Players can go at their own pace and repeat stages, and a voiceover is available for people who can’t read the screen.



Phil says the idea of a resource to help young disabled people handle money was first discussed two years ago with Merrill and John Holdsworth. The Holdsworth Trust is a longstanding supporter of the IHC Library.

“We wanted to do something with teens with intellectual disability who were thinking of moving out of home. We knew that our initial audience would be people who were tech savvy,” Phil says.

The Holdsworth Trust donated \$20,000 in seed funding to explore the idea of an online app with local digital technology company Optimization. Feedback was sought from people with intellectual disabilities and a parent of a teenager.

“It was teasing out what an online application would be and identify what some of the issues were for people who were looking to live independently,” Phil says.

“In the end we came up with the idea that we wanted something fun in the form of a game that would help people with money.”

A brief was written and IHC approached InGame, a gaming developer with a background in interactive training and educational games.

More money was needed to develop the game, and the timing was right. Post COVID-19, the Ministry of Social Development (MSD) had funding available for initiatives to help people with disabilities stay active and connected in their communities. IHC received \$75,000 from the fund.

“We were successful up to a point. We got about half of what we were asking for. Funding from MSD is going to enable us to get to the point of a working prototype, but not a published app. But it will have all of the elements of the game that will be expanded in the published version.”

It will also be something to show potential funders. IHC is now seeking a further \$100,000 to finish the project and to make the app free to download.

Top: The new app will provide a fun way to help young disabled people handle money.

Above: Stand Tall is the working title of the prototype.



IHC

Atawhai Nursery helps to rescue rare

North Taranaki's old and rare pōhutukawa – at risk from either falling into the sea or myrtle rust disease – have been given a second chance at survival.

A partnership between an IHC plant nursery, local iwi and the Department of Conservation is ensuring a new generation of young plants will soon be growing on the cliffs at Paparoa Reef, south of Wai-iti – but not quite so close to the edge.

Atawhai Nursery, near New Plymouth, is a commercial nursery run by IHC company IDEA Services. Nursery staff and volunteers have raised more than 200 plants taken from cuttings from the Paparoa pōhutukawa and they are now being planted out at sites selected by Ngāti Mutunga and botanist Marlene Benson, who first identified the trees in 1994.

At Atawhai Nursery volunteers with intellectual disabilities raise plants and learn skills that will help them transition to

paid employment. Nichola Manning, who leads the team of support staff, jumped at the chance to be involved in conserving the special trees. Nichola, who studied horticulture at Lincoln University, is keen for the volunteers to develop their skills and for the nursery to get involved in community projects.

The first nine trees are being planted at local primary schools – three trees each at Mimi School, Urenui School and Uruti School. Other planting sites selected by



The pōhutukawa (*Metrosideros excelsa*) are a member of the myrtle family and highly susceptible to the disease. They are also located on the edge of a steep, eroding cliff and falling into the sea.

Marlene says the Paparoa trees are important for two reasons. According to Ngāti Mutunga, these trees – some of them at least 500 years old – were brought by the waka Tokomaru from the Kermadec Islands and are sufficiently unique to have a special story to explain them.

They are also the southernmost known natural stand of pōhutukawa. Marlene and Nichola first took cuttings in 1997 to ensure this particular form of the species survived. It has a smaller leaf and different flowers to the cultivated varieties.

“I think we have lost at least half the pōhutukawa from my first visit over 20 years ago,” Marlene says. “Hardly any of the big ones are left. We counted the rings of one of the biggest and that was 500 years old.

“There was a big one on the riverbank where they used to cross. That died about 10 years ago of old age.”

Nichola and Marlene took three further sets of cuttings in 2017 and 2018. It was a risky thing to bring something into the nursery that had the potential for contamination, and they had to follow an agreed biosecurity protocol with the Ministry for Primary Industries for taking and transporting the cuttings.

Atawhai has been very successful in propagating the cuttings – about 70 percent have developed into young plants. “Some of them are big. Ninety-four of the bigger grade are up to one metre. They are a good solid plant.” Nichola says there are a further 120 or so in the mid-grade.

“It’s amazing. I am really pleased,” says Marlene, who has been working on the project for nearly 30 years. “Ngāti Mutunga are really excited.”

Left: Staff and volunteers at Atawhai Nursery in New Plymouth raised more than 200 young plants. From left, Hemi Sundgren, botanist Marlene Benson, Jamie Tuuta, Sarah Wright, Beren Hughes, Anne-Maree Mckay, Jaime Schrader and Atawhai team leader Nichola Manning.

Below: Nichola and Anne-Maree deliver the first of the new generation of Paparoa pōhutukawa to the Ngāti Mutunga marae office in Urenui.



pōhutukawa

Ngāti Mutunga include QEII protected land near the Mimitangiatua River mouth and a natural basin set back from the cliff edge at Paparoa. Marlene says pōhutukawa will also be planted at Urenui Marae – “probably just the three at the marae because we want to put them back where they belong”.

In 2017 when Taranaki was hit by myrtle rust disease, the Department of Conservation was looking for a nursery to propagate new plants from a stand of very old pōhutukawa on Paparoa Reef on the north Taranaki coast.

Healthy homes project under way

Accessible Properties is carrying out improvements to IDEA Services properties throughout the country as part of a Healthy Homes programme. This will ensure homes are insulated and heated to the appropriate levels. Assessment of properties has started and those that need the most work will be given priority. Contractors will keep in touch with Service Managers to let each area know when Accessible Properties will be assessing properties and doing the improvements. Accessible Properties is committed to meeting the Government's requirements for providing healthy homes.

Workshops connect family carers

In May and June four 'wellness' workshops gave family carers the opportunity to connect with other parents of children with intellectual disabilities. The events were hosted by the IHC Family-Whānau Liaison team after speaking with carers who were looking for connections with others who could share their experiences. Each workshop had its own theme. In Levin the focus was on healthy eating and nutrition tips. Participants enjoyed a soup-making demonstration. In Whangārei families learned ways to minimise stress. In Auckland the workshop demonstrated practical ways for communicating through dance and art. The final workshop in Christchurch provided ideas for dressing with confidence, healthy eating and how to make your voice heard. The feedback from carers was positive and participants have asked for more opportunities to spend time with other parents and carers.

Tax rebates made easy

Donors to IHC now have an easy way to claim their 33.33 percent tax rebates on any donation to IHC – and other charitable organisations over the past five years. As a donor you decide whether to re-gift or keep your rebate. Supporters can sign up to supergenerous.co.nz to do this. Although there is no upfront cost, there will be an automatic charge of 10 percent plus GST taken out of the Inland Revenue donation tax rebate to pay for this service. IHC National Fundraising Manager Greg Millar says many New Zealanders aren't reclaiming this rebate that they are due from Inland Revenue. "This is a simple and quick way to do this. It's also simple to choose to re-gift the rebate to IHC if you wish."



IHC

Rhonda and Rex hit the road to spread the word

Rhonda and Rex started their road trip early on a crisp May morning, their car loaded with gifts for school libraries.

By the end of the day they had covered 170 kilometres and delivered books to 12 primary schools, ranging from the small, rural View Hill School in the Canterbury foothills to Pegasus Bay School on the coast.

Rhonda James and her brother Rex McGiffert, who has Down syndrome, were distributing four children's books about intellectual disability to each school on behalf of the IHC North Canterbury Association's Books in Schools project.

The plan is to help children understand more about intellectual disability and to promote the services on offer from the IHC Library and Family-Whānau Liaison service.

"It was mind-blowing for people that we were funding things for other people," Rhonda says. "One woman, who asked how long they could have them, was hugging the books to her chest. She said, 'Oh, I have got books and I don't need to pay for them!'"

The association, which two years ago delivered books to 45 pre-schools in North Canterbury, will have covered 18 of 38 primary schools by the time it finishes with this present shipment – all recommended

by the IHC Library and funded by the local association. The four books are: *All My Stripes* by Shaina Rudolph and Danielle Royer, *Don't Call Me Special* by Pat Thomas, *Tomas Loves...* by Jude Welton and Jane Telford, and *Why Are You Looking At Me?* by Lisa Tompkins.

Rhonda, who works for insurance company IAG, used her 'Volunteer Day' to deliver the books. She says she ended the trip "buzzing". "I came away feeling very proud of our committee and what we have done, and what we are doing to reach our communities.

"I feel like a preacher spreading the word on behalf of the library and the Family-Whānau Liaison."

IHC North Canterbury Association Chair Kay Pearce says the Books in Schools project is an initiative to connect to young families. "It's a real feel-good project," she says. "You are starting at that early age – and we get such good feedback."

The initiative has been so successful that other IHC associations are getting on board.

Above: Rhonda James and her brother Rex McGiffert launched a road trip to deliver free books to primary schools throughout North Canterbury.



VOICES

Timing is everything

Young Wellington woman Katrina Sneath has found work at a unique hotel in the New South Wales Blue Mountains.

Timing is everying. Katrina, 25, had completed two years at the University of Sydney's uni 2 beyond programme just in time to join the first intake of trainees in Australia's first social enterprise hotel.

Hotel Etico is a guest hotel in the historic Mount Victoria Manor that runs a work, training and live-in programme for people with intellectual disabilities.

Katrina doesn't believe that having Down syndrome means she can't do what her siblings do, and decided she wanted to study overseas. The University of Sydney's uni 2 beyond programme at the Centre for Disability Studies was the right fit.

uni 2 beyond supports people with intellectual disabilities to study courses for interest – called auditing – and take part in university life without enrolling in degree courses. Katrina studied a wide range of courses, from nutrition to creative writing, global challenges and Greek and Roman studies.

"It was an amazing experience," she says. "Not many people with intellectual disabilities have a chance to audit university subjects and to see what the student life is about. It made me more open to opportunities, especially the advocacy subjects, and also the new things I learned. They gave me new ideas for creating future opportunities and life-tasting."

And Jan McConnachie, Katrina's mother, says her daughter is tasting all that Sydney offers. "She whizzes around Sydney using Citymapper." Citymapper is Sydney's transport app. "She has got an enormous amount of confidence in managing public transport on her own in a city this big with a lot of alternative options."

Before Sydney's COVID-19 lockdown Katrina found a part-time job in a lawyer's office, but that ended with the pandemic. She has also worked for Side by Side Advocacy as a co-researcher on an inclusion project and she goes to gigs with Gig Buddies Sydney.

In November last year, just as Katrina was completing her studies at uni 2 beyond, Hotel Etico opened and Katrina was accepted for the first intake of trainees. She takes the

train from Sydney to the Blue Mountains each week, working three days and staying over in a staff apartment for two nights.

"The people are really amazing to work with. They are like family," Katrina says. "They have inspired me to look at the opportunities to work at different hotels too. We can work and learn there for one year."

The inspiration for Hotel Etico came from northern Italy and Niccolo Vallese, a young man with Down syndrome who made a success of working in a local restaurant. The hotels now operate world-wide.

Jan accompanied Katrina to Sydney when she started uni and has worked hard to set Katrina up to live as independently as possible.

"She's quite determined she's not going to come back to New Zealand," Jan says. "She loves the new experiences, excitement and opportunities of the big city with lots going on."

Above: Katrina Sneath spent two years at uni 2 beyond at the University of Sydney.

No killer instinct

Colin Bailey was in the first New Zealand team to compete in the Special Olympics. He won bronze in the freestyle event at Baton Rouge, Louisiana, in 1983.

He was 22 years old and a very strong swimmer but Lee Bailey, his mother, says he had no killer instinct to make him want to win.

“It took a while to get that killer instinct into him. He was happy just to swim.”

Colin first learned to swim when he was seven or eight years of age on a family boating holiday on Lake Rotorua – and discovered something he was extremely good at.

At Baton Rouge he competed, along with Peter Spijkerman, Brent Busby and Gordon Llewellyn, winning four medals and becoming the first team to represent New Zealand.

Colin no longer swims at Special Olympics events but plays 10-pin bowling and has represented the Hutt Valley at regional and national events.

Below: Colin Bailey loved to swim, then discovered he could be a winner too.
Photo: Stuff Limited



VOICES

Colin hangs up

There's a huge gap at Hirepool in Lower Hutt where Colin Bailey used to work. He's retired from the Hutt Road branch after more than 30 years on the job.

Colin's farewell barbeque was an emotional day for everyone as Hirepool staff from across Wellington, along with Regional Manager Stuart Drew from Hawke's Bay, came to say goodbye.

“He does leave a gap here – 100 percent,” Stuart says. “He swept the yard, kept it clean. No-one did it as well as he did. His work here was exceptional. He brought an excellent work ethic, a great sense of humour, a cheekiness.”

Stuart says he'll miss Colin sneaking up on him and giving him a punch in the ribs. “It wasn't just work; we were part of his extended family.”

He says employing Colin had been a success and Colin had worked to make it a success. “Years ago, someone came up with a great idea and he has stayed with us all that time. Colin still had to earn his way, which he did.”

Wellington Area Manager Rod Groombridge worked with Colin for only seven or eight years but has known him far longer through Special Olympics New Zealand. Colin was a champion swimmer and Rod's mother, Carol Groombridge, was the organisation's first national secretary.

Rod says Colin was held in high regard by all the staff and treated as an equal. He says that was obvious in how many turned up to his farewell. A special sign reading ‘Colin's Wash Room’ was hung over his work area.

“It was a funny old day. It was emotional really. We made that sign and we retired his broom.”



his broom

Colin had worked at Hirepool for longer than any of the team and through many of its former lives on the site – Projex, Hirequip and then Hirepool.

Hirequip used to hire out heavy equipment and when the trucks, diggers and huge road-sealing compactors came back clogged in mud Colin scoured their outsides with a water blaster and gave their cabs a dust-off ready for the next customer. He worked in all weather in gumboots, mask, leggings and a beanie to keep warm. In 2009 Hirequip presented him with a long-service award.

Hirequip's successor, Hirepool, relocated the heavy machinery to another location and Colin switched gears. "I washed everything, the whole lot – washed all the gear, lawnmowers and rotary hoes."

Colin started at Projex in 1985 or 1986, on work experience. He then took a year off to do the vocational life skills course at Petone Weltech before heading back to work.

Lee Bailey, Colin's mother, says he got the job through IHC, working one day a week at the start. Before long "he was doing five days and he wanted to do six, but we put our foot down".

This was a big commitment for Lee. "I would get up at 5.30am to get him to work. He went at 7am and was picked up at 2pm," she says.

Last year, however, things changed. Although Colin's job was waiting for him after lockdown, he was 59 and becoming increasingly tired. "Yeah, I would go home and sleep," Colin says. As well, his father Ken died in September and Colin and Lee were having to adjust to the changes.

Lee, now 80, says she is glad to give up the early start. And Colin enjoys helping Lee around the house and mowing the lawns. He usually visits his old workmates once a week.

Above: Colin's farewell barbeque was an emotional day for Hirepool staff. Colin had worked at Hirepool for longer than any of the team.



The town that says yes

In 50 years of indoor bowling tournaments Marjorie Bloor has never picked up a ball. But she has picked up a knife and buttered loads of sandwiches for the players' morning and afternoon teas.

This year Dannevirke celebrates a long and special relationship between its indoor bowling clubs and IHC. This is a town that has always said yes to supporting local people with intellectual disabilities.

It's the 50th anniversary of the Dannevirke Combined Indoor Bowling Clubs IHC Tournament and Marjorie has been volunteering at the event from the start.

Marjorie and her husband John live on the highway north of Dannevirke on the Piripiri

flat where, as teenagers, Marjorie and her friends would ride their bikes to work, racing each other into town.

"I used to live six kilometres away. We came from a farm up the road – a dairy farm. Mum and Dad shifted there from Norsewood when I was 16. I used to bike into Dannevirke to work. Dad used to let me take the car when it was wet," she says.

"I was in the bank. It started off with the Union Bank, which later amalgamated with the Bank of Australasia to become the ANZ Bank."

It was while she was working at the bank that Marjorie met John Bloor, also off a farm, and he soon joined the cyclists on the trip into town. Marjorie and John married, went

farming and had three sons. Then in 1963 their daughter Jennifer was born with an intellectual disability. Marjorie says there was no help on offer for families of children with disabilities until the town decided to step in.

"I remember when the IHC opened here, the Mayor [L J Appleton] called a meeting in the Concert Chamber in 1966," she says.

The Dannevirke sub-branch of the Manawatū Branch of IHC was formed at that meeting. John joined the committee, travelling many hours to and from Palmerston North for Manawatū Branch meetings. He was treasurer and became patron of the Dannevirke sub-branch. Marjorie also joined the committee and served as secretary and treasurer.



*“It was fun really,
all working together.
You really get to
know people.”*

Dannevirke was supporting local families with disabilities long before people started saying that it took a village to raise a child.

Spearheading that support were the indoor bowling clubs. They got together and decided to hold a tournament to raise funds for charity. There are only two indoor bowling clubs left in Dannevirke, but their support hasn't wavered.

Players come from Napier, Marton, Feilding, Palmerston North, Pahiatua and Wairarapa. They play for the afternoon at the Dannevirke Sports Centre in teams of four and there are four games of 40 minutes each. People with intellectual disabilities are encouraged to join a team.



Marjorie may not be a bowler, but she says her daughter is keen. “She went away to a tournament and she did quite well.” Jennifer Bloor, now 57, prizes the insulated cup from Rabobank that she won as a prize in the 2019 tournament. “She has her morning coffee in that.”

IHC Committee member Theo Henricksen says it's always great to see the delight on the faces of the disabled players when they go to the table to select their prizes. Theo is a former president and secretary of the committee.

Since 1971 the tournament has raised more than \$60,000 for people with intellectual disabilities, and former Dannevirke Combined Indoor Bowling Clubs president John Johnson says IHC has always been the beneficiary. In 2001 the total amount raised reached \$2000 for the first time and is tracking at about \$2000 a year. The tournament is heavily sponsored by local businesses, which provide goods for prizes and raffles, and hardly anyone goes home without a prize.

“The sponsorship from Dannevirke has been incredible,” John says.

The money raised comes from sponsorship, the sale of raffle tickets, and entry fees from the players. It pays for extras for disabled people supported by IDEA Services in Dannevirke.

There are three residential homes in Dannevirke and all the houses and residents have benefited with outings, new lounge suites, iPads and garden improvements. The vocational base in High Street has had a shade sail installed and concrete paving is going underneath.

John was president for close to 17 years and, still on the committee, he organises the tournament each year. He says he's not sure why IHC became the focus of all the bowling clubs' efforts.

“Somebody just came up with the idea. They tossed up. It was going to be IHC or St John's

or someone.” And having made the decision, they stuck with it.

The 50th jubilee was to have been held last year but the pandemic intervened and the tournament was rescheduled for July 2021.

Marjorie recalls that the catering used to be a lot more demanding than it is now. As well as morning and afternoon teas, they would provide hot lunches with the meat donated by local butchers, the Ronchis. “The midday meal only lasted three or four years,” Marjorie says.

The women of the IHC committee would turn eight loaves of bread into sandwiches. “It was fun really, all working together. You really get to know people.” The fillings have got a bit flashier over the years, and the standard egg and corned silverside have been joined by cream cheese and pineapple, and apricot, cream cheese and ginger.

“They love the savouries – lots of sausage rolls. They love the cream cakes,” Marjorie says. “It's amazing the amount of afternoon tea they eat.”

Dannevirke Combined Indoor Bowling Clubs Secretary Corriene Mitchinson has worked hard to make the 50th anniversary a special celebration, with speeches, printed T-shirts and a cake-cutting by Marjorie.

“The first event was held on 2 May 1971. In those days there were nine bowling clubs in and around Dannevirke. Now there are only two clubs – indoor clubs,” Corriene says.

“It gives me a real buzz when I see the money that we raise. It's so rewarding. We have such support from all the local businesses and from outside the district as well.”

Above left: The Dannevirke Sports Centre was full of players for the 2018 Dannevirke Combined Indoor Bowling Clubs IHC Tournament. Photo: Hawke's Bay Today.

Above: Longstanding IHC committee members Theo Henricksen (left) and Marjorie Bloor have worked shoulder to shoulder over the years.

Families self-isolate for survival

Northland families with disabled children are withdrawing from contact with other people because of the sheer stress of trying to manage the children with little support.

IHC Family Liaison in Whangārei Jim Callaghan says families are barely coping because of the shortage, particularly of respite care that would give parents and carers a break.

The problem can be made worse by a child being excluded from school or from the few respite facilities available in Whangārei, leaving nothing on offer.

If a child lives in Kaitiāia rather than Whangārei there is no respite at all unless their parents want to do a four-hour round trip to deliver and collect the child.

Jim says families might be offered respite hours, but there is nothing to spend them on. "We can't get support workers up here. They're like hens' teeth. I have worked with families who haven't had respite for two years," he says.

"These families become quite isolated because there's no respite available."

Jim says the situation is even worse for children with disability-related behaviour, or as children get older and stronger and the grandparents who used to help no longer can.

"I have families with 28 respite days and they can't use them. Mum and Dad don't get to go out together. They don't get to spend time with their other kids – it affects the whole family."

Jim says families stay home because it's

easier and they don't have to face people's disapproval or misperceptions about disability-related behaviour, especially if a child has ASD or a disability that isn't immediately apparent.

"If they have a meltdown in the middle of the mall, it goes to bad parenting because the disability is invisible."

IHC advocates attended a hui in Whangārei in May to talk about the difficulty of accessing education for children who need extra support. While education was the hot topic, it was only one of the major challenges that the families spoke of.

"Families just get on with it," Jim says. "What do you do? You just get up and put one foot in front of the other." Jim says there needs to be more respite facilities, particularly for those under six and young people over the age of 17, and more support staff.

NOTICE OF 2021 ANNUAL GENERAL MEETING

Notice is hereby given of IHC New Zealand Incorporated's Annual General Meeting to be held at:

10am, Friday 17 September 2021
The Rutherford Hotel
Trafalgar Square, Nelson

Draft Agenda

1. Calling of Meeting
2. Obituaries
3. Welcome
4. Apologies
5. Meeting Rules and Procedures
6. Confirmation of Minutes of the 2020 Annual General Meeting
7. Matters Arising from the Minutes of the 2020 Annual General Meeting
8. Presentation of Annual Report, including reports from the Board Chair, Group Chief Executive, Member Council and Board Committees
9. Board Appointments Committee – Appointment of Board Members
10. Election of Patron
11. Appointment of the Auditor
12. Annual Membership Subscription
13. General Business
14. Next Meeting
15. Thanks and Closing

2020/21 Annual Report

The 2020/21 Annual Report and financial statements will be available at the Annual General Meeting. They will also be available via the IHC website prior to the Annual General Meeting, at ihc.org.nz

Ralph Jones
IHC Group Chief Executive

Both doses done for most in services

Most IDEA Services frontline support workers have now received both doses of the COVID-19 vaccination.

IDEA Services has been busy ensuring staff and the people we support have the crucial information they need about the vaccination, communicating directly with the Ministry of Health and, at a local level, district health boards.

"We've been engaging with the newly appointed Disability Equity Leads, whose job it is to coordinate vaccinations for the disability sector," says IDEA Services Director of Nursing Prudence Lennox.

IDEA Services has also been using the Ministry of Health's recently released Supported Decision-making Framework to ensure the people we support can consent, or not consent, to vaccination.

"The majority of people we support can communicate their decision, but this framework is a crucial step for people we support who either cannot consent themselves or don't have a legally appointed representative to act on their behalf," says Prudence. "This will ensure a consistent approach nationally for vaccinators and providers."

In addition to the COVID-19 vaccine, the influenza vaccine is available to staff and the people we support. Staff have been offered free vaccinations and, as in the case of the COVID-19 vaccine, we have been communicating with the people we support to ensure they either consent or not consent to the flu jab.

Banks continue their disappearing act

Banks have put even more distance between them and their more vulnerable customers by ending cheques.

This leaves disabled people wondering how they can pay bills and withdraw money as bank branches continue to close in cities and towns all over New Zealand.

Cheques have now been consigned to history at ANZ, Westpac, BNZ, Kiwibank, TSB, SBS, Rabobank and The Co-operative Bank, and ASB finishes with cheques on 27 August. Some retailers are also moving away from cash payments.

Disability service providers, including IHC, are in talks with banks to see how disabled people can continue to do their banking as independently as possible.

The key issues were brainstormed at a Banking Issues Forum in March organised through a collaboration between the New Zealand Disability Support Network (NZDSN), IHC Advocacy, People First and the Bankers' Association. One of the more significant issues discussed was the requirement of some banks to have guardianship orders in place for people to be supported to have their own bank accounts.

Disability service providers have become increasingly uncomfortable with the systems that banks have in place to manage people's money on their behalf. Money-laundering legislation and the prospect of a world without cheques are also creating uncertainty – for providers and banks – resulting in different and changing requirements from bank to bank.

NZDSN Chief Executive Dr Garth Bennie says these are significant issues that require collaboration by banks, customers, service providers and government contract holders.

"It's like the technology has moved too fast for many people," he says.

"What's needed is for banks to find a way to identify and meet the needs of customers with learning disabilities, and to provide tailored assistance to these customers.

"It's complicated and the banks are not allowed to collaborate in the way that we would want them to because of anti-competition rules," he says.

"We need the Ministry of Health on board as well, because there's a need to make changes to contracts to enable providers to do things differently."



Garth says ideally if people need support with their banking there should be a system that triggers a response to verify their credentials - and those of anyone supporting them - and allows them to proceed with their banking. He says the banks acknowledge the challenges for families and support staff, but they need assurances around the risks and the help of service providers with the solution.

"They want certainty around the fact that the person supporting that individual is the real deal," he says. "Agreeing and getting the details of what needs to be in the banks' systems to verify the individual and the person supporting them is the tricky thing," he says.

"The reality is that once the person has a bank card and a process in place to use that, then that person doesn't really need to go back to the bank that often."

Service providers are now working with the Ministry of Health on a template or set of guidelines to take to the banks.

Above: As banks stop cheque payments and some retailers move away from accepting cash, many people are wondering what to do.
Photo: Aneta Pawlik – Unsplash

Jeremy's life choices open up

The small Rangitikei town of Hunterville doesn't have a lot to offer for a young man at weekends.

So it's understandable if Jeremy Hill-Hayer decides to stay on in Palmerston North to go to a disco rather than travel home to see his parents.

Life has changed a lot for Jeremy since he moved into an IDEA Services residence in Palmerston North a year ago and signed up with a Choices NZ life coach.

Jeremy, age 31, has a disability that makes it hard for him to make friends and stay safe in his community. But despite that his calendar is now full of activities and people thanks to targeted help that has given him new skills and confidence.

Fitness is a big part of Jeremy's week. He works with Choices NZ Life Coach Ruben Anderson twice a week and they swim, go running and work out at the gym – setting goals for physical fitness and life.

"Yes, I like it. I like the weights best," Jeremy says. "I do feel better."

The fitness programme paid off when Jeremy joined the IDEA Services 'Pirates' team to compete in the Cancer Society's Relay for Life Manawatū in March.

"Jeremy camped out with the team overnight, crashing for a few hours' sleep in the team's house bus that we parked up at the side of the track," says IDEA Services Manawatū Area Manager Karen Wilton. "His Mum travelled to town and even walked a couple of laps with him and the baton." Jeremy's Relay for Life T-shirt is a very proud addition to his wardrobe.

Ruben's support complements other activities with IDEA Services during the week – art classes, a walking group, the Manaaki Tangata kapa haka group and monthly Friday night discos in Feilding.

A huge leap forward for Jeremy has been getting the knack of catching the bus around Palmerston North by himself. "I go on a bus and look around shops. I normally just go to the mall. If I get stuff out of the library, I take stuff back to the library."

Jeremy says he also looks for CDs and DVDs at the Salvation Army shop. Music is a key interest he shares with his older brothers, who are musicians, and guitar lessons are on his list of goals.

Jeremy will soon move out of a group home into a supported flat. "He's learning to be a lot more independent," says Service Manager Marie Pascoe. "We're working together to make sure he's interacting with a lot of different people. The long-term goal is to get a part-time job."



Jeremy's mother, Carla Hill-Hayer, was struck by how Ruben had been able to encourage Jeremy with reading after Jeremy read to her one day. "It was some kind of notice he had about something. He was able to read it to me and it was really very moving," she says. "We are so proud of the progress he has made."

Carla lives 12 kilometres north of Hunterville. "It's quite remote. It's beautiful but it's not very good for Jeremy. Of course, coming here

from Auckland was quite difficult for him," she says. "If Jeremy had a disability that people could see, people would be more understanding."

Above: Carla Hill-Hayer travelled to Palmerston to walk a couple of laps with Jeremy and the baton in the Cancer Society Relay for Life Manawatū.

Below: A job well done. Jeremy celebrates with Service Manager Marie Pascoe.



Michael honoured for a lifetime of sporting achievement

Michael Holdsworth was made a Member of the New Zealand Order of Merit in the Queen's Birthday Honours, making him the first person with Down syndrome to receive this honour.

He was awarded the MZNM for his services to Special Olympics and it marks his 32 years as an athlete leader, advocate and participant in two World Games and his service to the New Zealand Down Syndrome Association.

Michael is passionate about sport of all kinds – especially the Hurricanes – which created an immediate bond with TVNZ Breakfast presenter John Campbell during an interview about his Queen's Birthday Honour.

Breakfast co-host Jenny-May Clarkson asked Michael what was wrong with the Hurricanes – but John jumped in and told Michael not to answer the question, saying there was nothing wrong with the Hurricanes. "I agree with John there," Michael answered, telling John that his favourite 'Cane' was Ardie Savea.

"I am quite proud to be the first Kiwi with Down syndrome. I am really proud and my family is proud with all the years I have done for the sport," he said.

Michael has been a competitive alpine skier and swimmer in Special Olympics New Zealand events in New Zealand and overseas. He has competed at the Special Olympics World Winter Games in Austria twice – in 1993 and in 2017.

In 2010 he was named one of Special Olympics' first Global Messengers – ambassadors working in the community to promote the impact of Special Olympics on the lives of people with disabilities. In that role he has presented at seminars around New Zealand. He was a guest at the 2015 Special Olympics World Summer Games in Los Angeles, where he presented a medal at the swimming competition. In 2017 he was given the honour of lighting the Flame of Hope together with the New Zealand Police Assistant Commissioner in the lead-up to the Special Olympics Summer Games in Wellington.

In 2019 Michael was part of a team involved in coaching young children with intellectual disabilities through the Special Olympics Young Athletes sport and play programme.

Michael is the longest-serving staff member in the IHC Library, where he's worked for nearly 27 years. He works on the front desk



at the library, greeting visitors and dealing with enquiries. He also mentors people who come to the library on work placements.

IHC Group Chief Executive Ralph Jones says Michael has always been a committed sportsman.

But this award recognises his role in supporting and leading others to participate and achieve.

Above: Michael Holdsworth is a world-class alpine skier, competing at the Special Olympics World Winter Games in Austria in 1993 and 2017. He won a bronze medal in 2017. Photo: Special Olympics New Zealand

Human rights experts hear from parents

IHC now has some powerful support in its long-running legal battle to protect disabled children's rights to a proper education in mainstream schools.

The Human Rights Review Tribunal and IHC are collecting evidence about the experiences of disabled children in the education system from parents, educators and community groups, ahead of a hearing in that tribunal.

The claim was first lodged against the government in 2008. It has taken 13 years to get to this point. The ground finally shifted in favour of a legal resolution late last year when the tribunal dismissed an attempt by Crown lawyers to strike out key aspects of the IHC case. The Director of Human Rights Proceedings Michael Timmins then agreed to provide legal representation to IHC.

Michael, human rights lawyer Josh Suyker and IHC advocates began attending meetings with parents in Whangārei in May. They heard first-hand accounts of the discrimination young disabled Kiwis face at school. Two further meetings were held in Auckland and others are planned throughout New Zealand. IHC is compiling a growing list of people who want to share their experiences.

This is also an opportunity for others in the education, disability and community sectors to tell the tribunal what they think about these problems and how they could be solved.

Examples of discrimination include disabled students being denied enrolment or not being able to attend school all day, being encouraged to go to a school that is 'more appropriate' for disabled students, not participating in school activities, or being placed with a teacher who lacks the confidence or support to teach students with different learning needs.

Many students can't access the support they need for equal access to education.

In 2019, in an IHC survey of 300 parents of disabled children, 27 percent said a school had refused to enrol their child in the preceding five years, and 58 percent reported their child had been bullied.

IHC believes these practices contravene New Zealand's commitments to international human rights conventions.

IHC Director of Advocacy Trish Grant says there are many stories of discrimination in New Zealand schools, and the Whangārei hui brought even more to light.

"There was a lot of feeling in the room. A lot of sadness and frustration expressed, a lot of despair, a lot of anger."

Michael Timmins is asking families and carers:

- What difficulties have you and your child faced at school?
- How did you go about trying to solve those problems?
- What changes do you think need to happen for your child and other disabled students to get a fair deal?

Trish says the human rights experts will now decide whether disabled students can exercise their right to education free from discrimination. She hopes the hearing will be held this year.

Anyone wanting to host a meeting, attend a meeting or support the complaint can contact the Advocacy team on 04 472 2247, 0800 442 442 or advocacy@ihc.org.nz

Read more about the education complaint at ihc.org.nz/ihcs-education-complaint

Below: Director of Human Rights Proceedings Michael Timmins hears from parents at a hui in Whangārei in May.





IHC

Young artists seize their chance

Eight young artists have their eyes on a new prize in the IHC Art Awards 2021.

The Youth Award is a new category in the IHC Art Awards this year, for artists aged between 13 and 17 years. When entries closed on 31 May, eight of the 356 artists entering were in the Youth Award category. The winner of this award stands to win \$1500.

These artists are also eligible for the overall award of \$5000 and the L'affaire People's Choice Award of \$2000.

The winners will be announced at the gala awards night, to be held at the Museum of New Zealand Te Papa Tongarewa in Wellington on 30 September.

General Manager of IHC Programmes Janine Stewart says the decision to introduce the new category will ensure that up-and-coming artists are seen and celebrated on a national stage.

Another innovation this year is the participation of Wellington coffee company L'affaire as sponsor of the People's Choice Award. L'affaire was established in Wellington in 1990 and is a pioneer of New Zealand's café and coffee culture.

L'affaire first became involved with the IHC Art Awards in 2020, when it hosted a special exhibition of top artworks in its flagship roastery and café in Wellington.

Auckland artists Otis Frizzell, Judy Darragh and Paul Hartigan will judge the IHC Art Awards this year. Jewellery designer, vocalist and former IHC judge Boh Runga will MC the event.

This year IHC Art Awards Ambassador Dame Denise L'Estrange-Corbet visited students at Opunake High School in March as part of her role to promote the awards. She also visited artists at The Papermill in Whangārei, the Manaaki Ability Trust in Lower Hutt and Aranui in Kilbirnie, Wellington. Dame Denise

is co-founder of WORLD fashion house. She also creates opportunities for top IHC Art Awards artists to raise their profiles in the fashion and art communities through the WORLD Legacy Charity Project.

The IHC Art Awards is an annual showcase of the talent and achievements of people with intellectual disabilities.

More details, including dates for the L'affaire People's Choice Award voting and online auction, will be available at ihc.org.nz/art-awards-2021.

Above: Wellington artist Elyzah Warda is working on a painting of her boyfriend when Dame Denise L'Estrange-Corbet visited artists in Kilbirnie in Wellington. Elyzah has entered the 2021 IHC Art Awards.



VOICES

Poppy inspires young movie-goers

Poppy – starring Libby Hunsdale and Ari Boyland

Writer and director – Linda Niccol

Poppy reached the big screen in May and struck a chord with young women refusing to be defined by their disabilities. Ella Davenport from Lower Hutt and Ava Saba from Gladstone reviewed the movie.

By Ella Davenport (with some help from mum)

I went to see the movie *Poppy* with my mum. It's a story about Poppy's life. She lives with her older brother and she pretty much takes care of the house.

Her dream is to do a mechanic apprenticeship and get her driver's licence. But her brother thinks it is all too hard for Poppy and doesn't really help her. He loves her though and is very protective of her, especially when she meets a boy she really likes, and he tries to stop them dating.

But Poppy is determined to go after what she wants. She wants to live her best life and by the end of the movie she sure is. She has an apprenticeship, a flat, a boyfriend and her driver's licence. She's also amazing at doing burnouts in her boyfriend's car and I cheered her on from my movie seat. She even finds her brother a girlfriend.

Poppy is proof that having a disability doesn't need to hold you back or stop you from chasing your dreams. When I think of *Poppy*, this is how I would describe her: independent, smart, funny, caring, feisty (very). But the one word that sums her up for me is awesome.

Poppy inspires me to want to live my best life too. Thank you Poppy.

Ella, 20, goes to Hutt Valley High School and has a couple of work experience jobs, at a charity shop in Petone and a café in Lower Hutt. She has been dating her boyfriend, Nicholas, for a few years. He has Down syndrome too. Ella was the winner of the Wellington Down Syndrome Association's Frances Clarke Memorial Award in 2015.

By Ava Saba

I saw *Poppy* with my mom, Hutch (stepdad), Zack, Finn (brothers) and Romy and Lorena (brothers' girlfriends). It was a special fundraising show for Wairarapa Riding for the Disabled. I used to ride there when I was little on Tara the brown horse.

I thought the movie *Poppy* was nice and romantic. It made me cry once. It was a happy/sad cry. It was when she was in love with the nice boy.

Poppy is cool because she drove a car and did wheelies. I want to drive a car one day,



when I am a grown up. Poppy is beautiful and I got to meet her. Her real name is Libby. She was so nice. I want to do acting in a movie like her one day. I also want a nice boyfriend one day too.

I am going to see it again with my friend Sophie. *Poppy* made me feel happy.

Ava, 15, lives in Gladstone, Wairarapa, with her mum and step-dad. She has two older brothers. Ava goes to Wairarapa College and is in the swim team and plays netball. She loves dancing, performing arts, swimming and hanging out with her friends. She is the current recipient of the Frances Clarke Memorial Award for her achievements in performing arts.

Top: Hutt Valley High students Ella Davenport and Nicholas Baldwin are pushing the boundaries.

Above: Ava Saba hopes to one day be an actor like *Poppy* star Libby Hunsdale.

Tayla shares her awesome life

Tayla Sloot sees a lot from her wheelchair. And she knows that her disability is a barrier that prevents people getting to know her.

But worse than that, Tayla knows her wheelchair can be frightening for young children. She's seen young children hide behind their parents, too scared to approach her.

Tayla, 25, thinks this is because children have limited awareness of those who have disabilities, and her solution has been to write a book about her life to reach out to school children.

"I want to tell others that don't know about disabilities or cerebral palsy," Tayla says. "For me, I find it hard to sometimes get my words out, and being in a wheelchair I have to get some help to get around."

She says people are often in too much of a hurry when they encounter disabled people. Her goal is to change attitudes, starting with children.

In *My Life with Cerebral Palsy*, Tayla answers some of the questions that children might want to ask about her disability and what it's like being in a wheelchair. But Tayla's book is also full of photographs and she's open about her life and what she achieves every day. She lives in a flat, is a member of a drama group, and does voluntary work.

"I have written this book to talk about my disability. I would like to share what an awesome life I live and the cool things I get up to," she writes.

"I hope after reading my book you will know more about me and you won't feel shy to come and talk to me."

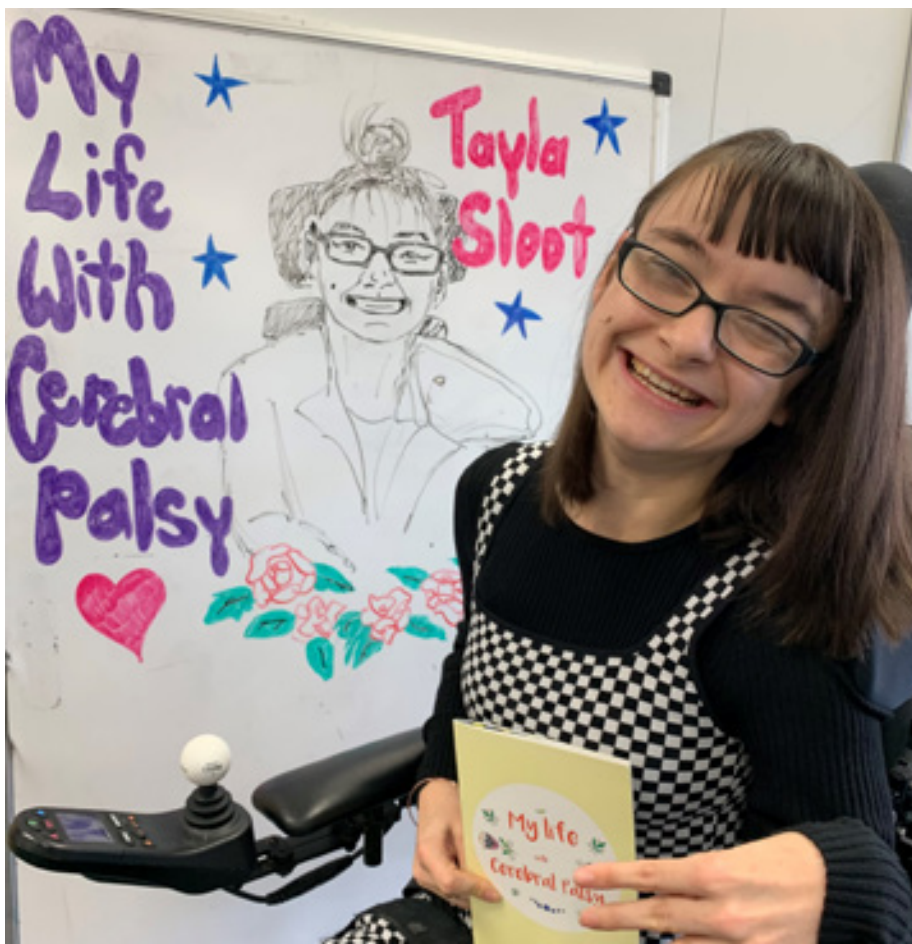
Her book has been six years in the making. With support from IDEA Services staff at Switch in Dunedin, Tayla has written it, illustrated it and raised \$1000 to get it printed. In 2017 she held a quiz night to raise funds to cover the cost of publishing the 28-page book. To help Tayla share her message, Dunedin Print decided to boost the number of copies she could afford to print – only 32 – to 320.

Tayla says her main message to people who read her book is, "I enjoy the same things that you enjoy."

In May she launched her book to a room full of family members friends and supporters and more than a few tears.

Her next step is to send copies of her book to Dunedin schools and other organisations to spread her message to a wider audience and help more people understand cerebral palsy and how amazing life can be. Tayla will give her book and a presentation to her former schools in Dunedin.

Below: Tayla Sloot is keen to share her story with young people and answer their questions.



IHC NEW ZEALAND INCORPORATED IHC.ORG.NZ

IHC BOARD

Tony Shaw, Chair
Ralph Jones, Chief Executive
Andy Evans
Dr Lynne Lane
Barbara Rocco ONZM
Suzanne Win

IHC MEMBER COUNCIL

Barbara Rocco, Chair, ONZM
Mark Campbell
Janet Derbyshire
Anne Gilbert
Dr Diane Mara MNZM
Vicki Owen
Kay Pearce
Cassy Williams

PATRONS

Sir Roderick Deane KNZM and
Gillian, Lady Deane CNZM

NZ LIFE MEMBERS

Dr Terry Caseley
Sir Roderick Deane KNZM
Jan Dowland MNZM
John Hanning
Christine Lee
Shelley Payne
Lynne Renouf
Barbara Rocco ONZM
Tony Shaw
Neil Taylor QSM
Maureen Wood MNZM

IHC NATIONAL OFFICE

Level 15, 57 Willis Street,
Wellington 6011
PO Box 4155, Wellington 6140
Ph 04 472 2247, Fax 04 472 0429

EDITOR

Gina Rogers
Ph 04 495 2771
Email editor@ihc.org.nz

COPYRIGHT

Strong Voices is published by IHC New Zealand Incorporated. The content of *Strong Voices* is copyright. No part of this publication may be reproduced or transmitted in any form or by any means without the prior written permission of the publisher.

ISSN 2744-3949



Give the gift of a meaningful life

A gift in your Will can bring meaning, purpose and joy to the lives of people with intellectual disabilities.

To find out more please contact Lisa Marshall
on 0800 746 444 or lisa@ihc.org.nz

ihc.org.nz/bequests

ihc
IN YOUR COMMUNITY