

# StrongVoices

EMPOWERED LIVES



Autumn 2022

40 years and  
counting

Patrick has the fight of his life  
Who cares for the carers?





# Kōrero

It doesn't help to complain – but I'm sure that many of you will share my frustration that we have headed into another year with COVID-19 restrictions in place.

Complying with those restrictions to keep everyone safe, combined with a lack of, or slow, advice for our sector, has been complicated.

It is possible that we could see quarter of our staff away at any one time with illness or because they are a close contact of someone with COVID. Making sure we have staff to run all our disability and tenancy services, as well as our charitable programmes and essential back-offices functions, is going to be a real challenge. I know our local staff are getting in touch with many of you about how you may be able to help.

While COVID is causing delays to some of IHC's long-term projects, having to work differently out in the community has forced us to work better.

IHC's volunteer friendship programme has been as important as ever with people staying in touch online, waving at each other through windows or dropping gifts and messages off at people's gates during lockdowns. But we have also had volunteers ringing people and responding to immediate need – getting groceries or other supplies, connecting people with formal or informal support or arranging respite.

We are better connected too with younger families. We support online communities, such as Awhi Ngā Mātua, where fun, frustration and advice are shared. Our library has been as busy as ever responding to requests for information.

Our three op shops remain open for now but, like every other retailer, it has been a bit of a roller coaster. Around 140 volunteers help to keep our shops running.

In the lead-up to Christmas we presented some fun online sessions. We had great feedback about these arts, crafts and music sessions and a disco. People mostly tuned in from home – some in IDEA Services homes, some in supported living and others living with their families. We are keen to do more of this kind of thing. Watch for updates.

Also keep an eye out for news about the Money game. This online game, which teaches young people with intellectual disabilities how to manage money, is in the testing phase. We expect it to be available in the next few months. It's been codesigned and developed with disabled people, so the learning scenarios have been chosen by those in the know. The game's development is partly funded by Ministry of Social Development COVID-19 funding and will be available either online or as an app.

The Art Awards is now in its 19th year. Last year when we had to cancel Gala events because of COVID, we opened a pop-up shop in Wellington to sell the top 85 art works. All but a couple sold, which was fantastic.

All of this is possible thanks to donations. I know many of you are donors and I would like to thank you again for the difference you make.

I dearly hope that 2022 is a good one for all of us. Please stay safe and kia kaha,

**Janine Stewart**  
General Manager, IHC Programmes

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### COVER IMAGE:

**Heavyweight champion – For years two Hamilton DairyNZ research and development farms have fought it out to see who can raise the heaviest calf. In 2016 Kristoff from Lye Farm, at 225 kilograms, beat his rival from Scott Farm by 50 kilograms. The four-month-old calf was pampered and preened by calf-rearer Ashleigh Wenham, scoffing warmed milk morning and night along with some secret blend of moozlee and molasses, hay and lush pasture grass. See story opposite page.**



IHC

## Caps off to farmers for 40 years' support

**It was a quirky idea – donate a calf to IHC and get a pair of gumboots. But for some reason dairy farmers said, “Count on us”.**

And for 40 years IHC has counted on their support to the tune of \$40 million, on average \$1 million a year.

This year we celebrate the 40th anniversary of the IHC Calf & Rural Scheme and the farmers, volunteers and rural businesses who feel so strongly about backing those in their communities who need support. The scheme has also caught the imagination of rural-based companies such as long-time sponsors PGG Wrightson, Volkswagen and livestock identification company Allflex.

More than 10,000 farmers have donated calves to the scheme, some of them have donated multiple calves for many years, through thick and thin.

“And when they are asked why they do it, the answer often is, ‘It’s just what you do,’” says IHC National Fundraising Manager Greg Millar. Practically speaking, it has worked for farmers who might be cash poor but happy to raise a calf for IHC along with the rest of their herds.

“We are incredibly grateful to the many

farmers who have supported us over the years, some of them down through generations of farming.”

One other farmer stands head and shoulders above everyone else in his support of the fundraising scheme. All Blacks legend Sir Colin Meads became a rural legend when he threw his weight behind IHC after retiring from playing rugby, and we were privileged to have the backing of the big man from 1974, for more than 40 years until his death in 2017.

Long before he became Sir Colin in 2001, he was generous with his name and his fame, using his high profile and mana for the benefit of people with intellectual disabilities.

He was a natural fundraiser and supported the two farmers, Norm Cashmore in Taranaki and Mick Murphy in Blenheim, who started the IHC Calf Scheme in 1982. When the farms got bigger, Colin told the large-herd owners to think about donating even more calves. They did. He also encouraged his fellow beef farmers to join in.

In the 1980s, Sir Colin donated the proceeds of his speaking engagements towards the purchase of a farm in Te Kūiti for people with intellectual disabilities. His idea was

to provide employment and teach farming skills. Pinetree Farm became a drop-off point for donated calves on their way to the sales. It’s still used today for local support and residential services.

Sir Colin and Verna, Lady Meads, always worked as a team in their dedication to IHC’s cause and made a huge difference to the lives of many people with intellectual disabilities and their families. Verna died in December last year.

DairyNZ, which has supported the IHC Calf & Rural Scheme for 20 years, has liked having some fun along the way. Lye Farm and Scott Farm, two DairyNZ research and development farms on opposite sides of the road in Hamilton, have for a long time battled it out to see who can raise the heaviest calf.

Like the farm staff rearing the Lye and Scott calves, many others have chosen to give their biggest and best for the benefit of people with disabilities. Others have chosen to buy the calves and rear them on for even larger prices for IHC.

**Above: Heart and soul – Long-time supporter Sir Colin Meads celebrates the 25th birthday of the IHC Calf & Rural Scheme at the IHC Tarr Road farm in Cambridge with staff and people supported by IHC/IDEA Services in Waikato.**





IHC

# Shelley's roots go deep in IHC

**Former IHC Vice President Shelley Payne was made a Member of the New Zealand Order of Merit in the New Year's Honours, for services to people with intellectual disabilities.**

It was recognition of the 23 years during which Shelley used her energy, business acumen, courage and warm good humour at every level of IHC.

The Tauranga hotel owner joined IHC in 1995 and became involved because of her son Ryan. Ryan had multiple disabilities and Shelley was determined that he would have the best life he could have.

But Shelley's roots with the organisation go deeper than that. Her uncle Guy Ivil had Down syndrome and his father – Shelley's grandfather Lawrence Ivil – was the first president of the New Plymouth branch of IHC in the 1950s.

When Lawrence and Shelley's father Kerrin died within a short time of each other, her uncle Guy and her mother Nola came to live in Tauranga with Shelley and her husband Geoff. Guy then moved into IHC residential services in Mt Maunganui.

It was Nola who first joined the local branch of IHC and encouraged Shelley to get involved. The rest is history. By 1997 Shelley was President of IHC Mid-Bay of Plenty Branch. By 2002 she was working at a national level on the IHC New Zealand Board.

Self-advocacy was Shelley's passion and her experiences with Guy and Ryan helped her to connect with the self-advocates – individuals with intellectual disabilities who wanted a greater say over how they lived their lives. This was the time when people with intellectual disabilities were moving out of institutions to live in communities.

Shelley's role as a director of IDEA Services was to present her with one of the toughest challenges of her time with IHC. In 2010 IDEA Services went into voluntary statutory management as it could not afford to pay workers court-ordered backpay for sleeper shifts. As a director of a company facing substantial personal risk, Shelley nevertheless supported the statutory management process.

"That statutory management period was a moment in time when much could have been lost, or we were going to move forward into something much stronger." Shelley says the development of the IHC property portfolio – building on the hard work of many families over many years – has given IHC the financial stability it needs. "The property portfolio will ensure that IHC will be there for as long as parents want it to be there."

While Ryan's multiple disabilities meant he was never able to live independently, Shelley wanted her son to have options. Ryan moved to an IHC residence when he was 21 and shared accommodation with four young men and loved it. She says he became "an absolutely different Ryan".

"They actually find that little sense of independence. I was over-mothering and over-protecting and making all his choices. But here was this whole other person tucked away."

Shelley chaired the Self-Advocacy Advisory Committee of the IHC Board for 12 years and was determined that the voices of those with disabilities would go through to the Board as an authentic source of advice about the community services IHC provided.

Shelley was also working hard in the Bay of Plenty. She committed to a new organisation – the Arohanui Art and Education Trust. The Trust was a community vocational service delivering individually tailored programmes to people with disabilities. Shelley was a trustee from the time it started in 1999 and has been Chair since 2003. Ryan attended the Arohanui studio in Te Puke for nine years until his death in 2011.

Shelley retains her connection with IHC as a trustee of the IHC Foundation.

**Above: Shelley Payne has devoted her life to making sure people with intellectual disabilities can live the best lives they can.**

# Gene team finds the answer to a 21-year-old puzzle



## RESEARCH

**The Sterne family has spent much of the past 21 years wondering whatever happened to Luke. Now, thanks to genetic researchers, they have the answer.**

“When he was born I was a week overdue and he was severely growth-retarded, severely underweight,” says Luke’s mother Nicola Sterne.

Nicola was 33 when Luke was born in 2000, the Sternes’ second child. Nicola says she recalls feeling there was something wrong.

“He was induced. It was a horrific time.” She says an explanation from a doctor at Auckland’s National Women’s Hospital didn’t help. “She said, ‘He has an even chromosome translocation and we don’t know how that is going to manifest itself.’”

“So I went home with this baby and literally went through six weeks of hell.”

Luke wasn’t able to feed. “He wasn’t strong enough to swallow the formula. He was shaking because he was so malnourished,” Nicola says.

She returned to National Women’s Hospital and Luke was sent to Starship Hospital, where he was given the immediate help he needed. But as for what was actually wrong, no one knew. “His blood was sent to Germany and they couldn’t find anything wrong; they couldn’t find anything missing.”

Fast-forward to 2016, and Luke was recruited into a study being carried out by Minds for Minds genetic researchers at the University of Auckland’s School of Biological Sciences and Centre for Brain Research to find the genes and genetic variations responsible for rare conditions.

Luke’s younger brother Kyle recalls that it wasn’t plain sailing collecting blood from him. “I think they nearly gave up,” he says.

But it was an opportunity they couldn’t pass on. “It was so important for my other children to know,” Nicola says. And two years later they did, receiving a call from their clinical geneticist. “She said, ‘Well, it’s good news. He has a syndrome – DYRK1A, a gene involved in brain development. Changes in the DYRK1A gene have been linked to intellectual disabilities, microcephaly, speech and language impairment, seizures and autism.’”

“It was a bit of a sad day because you know there is actually something wrong,” Nicola says. But it also provided some answers and certainty for the family.

Despite not knowing what had caused Luke’s disability, Nicola and husband Richard had a third child, Kyle.

**Left: Random – The cause of Luke Sterne’s disability was a first-generation genetic mutation.**

*Continues on page 17.*



**Down for Love**

TVNZ's new dating show *Down for Love* is set to screen soon on TV2. Filmed by Attitude Pictures, *Down for Love* follows six young adults with Down syndrome on their quest for romance. Finding soulmates is top of their list and the series follows them from Rainbow's End in Auckland to Larnach Castle in Dunedin, and mini golf to a romantic harbour cruise. Each of them will take potential suitors on the dates they've been dreaming of. Along the way they will discover what to do – and what not to do – on the journey to find a partner. The series was created in consultation with the New Zealand Down Syndrome Association and made with the support of NZ On Air.

**Autism NZ launches 'Vaximate'**

Autism New Zealand has launched an online tool that supports autistic people looking to get COVID-19 vaccinations. Autism New Zealand Chief Executive Dane Dougan says Vaximate, a series of digital guides, takes people through the process so they feel comfortable. "Two of the most common reasons we hear that autistic people are resistant to getting a vaccination are needle phobia and having to navigate an unfamiliar environment. Routine is a key coping mechanism; knowing what's going to happen ahead of time helps people to navigate the 'everyday' and to feel safe." Vaximate is found on Autism New Zealand's Facebook and Instagram pages and includes videos and step-by-step guides – on everything from making appointments to what to expect afterwards. Vaximate also has tips on how to stay calm.

**Have your say on restraint rules**

The Ministry of Education is seeking public feedback on the rules and guidelines covering the use of physical restraint in schools. This is to make sure that the new rules are workable, uphold the rights of children, whānau and school staff, are clear about when and how physical restraint can be used, and prevent its use except as a last resort. The consultation is open until 31 March 2022. Visit [consultation.education.govt.nz](https://consultation.education.govt.nz) – search 'physical restraint'. See story opposite page.

# IHC urges sharper focus for next Disability Survey

**People with intellectual disabilities make up a small percentage of people in New Zealand with disabilities. How small? No one really knows because no one is counting them properly.**

This is why the 2023 Disability Survey being planned by Stats NZ is important – and why IHC has made a submission suggesting ways it can help people with intellectual disabilities to be seen and heard and counted.

The Disability Survey is the primary source for estimating how many disabled people there are in New Zealand. It also provides information on the experiences of disabled people, and how well they are doing across a range of housing, economic and wellbeing measures.

This is a once-in-10-year opportunity. The last Disability Survey was held in 2013 and IHC Advocate Shara Turner says it is still one of the primary sources of statistics we rely on to understand the lives of people in this demographic – together with an even older report, *Health Indicators for New Zealanders with Intellectual Disability*, published in 2011.

Shara says the present Disability Survey is more reflective of people with physical disabilities, who make up the majority of disabled New Zealanders. "We have a very small population of intellectually disabled people and their lives are very different."

She says questions about transport are aimed at those with physical disabilities. "For us, accessibility is not about a ramp, it's about how you get people to be able to afford to get on a bus." When it comes to barriers to employment, the barrier for people might be more likely to involve the interview. "The types of modification that a person with an intellectual disability might need is having a job interview where the

person can demonstrate what they can do."

Data needs to be presented in a way that explains more about the people we represent. For example, talking about people over the age of 65 is not particularly relevant when the average life expectancy for people with intellectual disabilities is 59 years, around 20 years less than general population. The Ministry of Education keeps no national records of the number of children with intellectual disabilities. "We don't know enough about who is in any age group," Shara says.

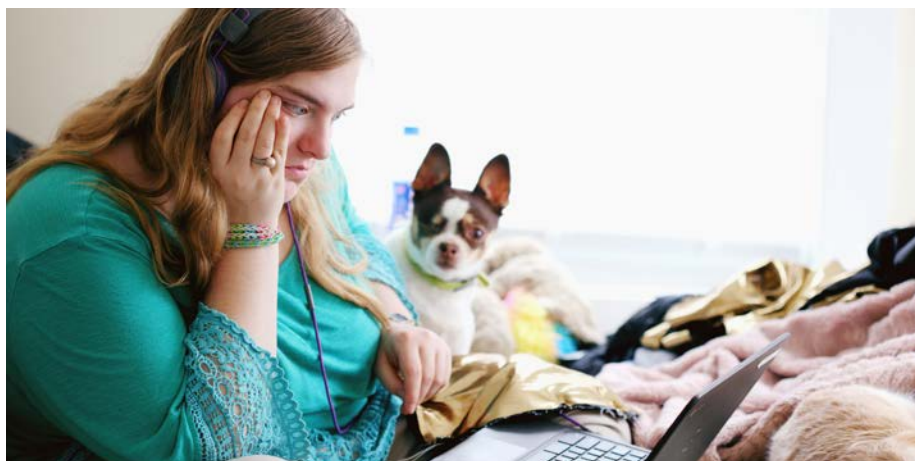
Last year, when the Government decided to make KiwiSaver available early to some groups of people who had conditions associated with shortened life expectancy, IHC thought it made sense to also lower the qualifying age for national superannuation.

"We wrote to [Minister for Disability Issues] Carmel Sepuloni to say can you make national superannuation available to people 40-plus? And they said no. There are no plans to do this," Shara says. "Imagine if people with intellectual disabilities got super when they were 40. It's a huge step up."

Shara says the IHC submission on the 2023 Disability Survey suggests a number of ways the survey could better represent people with intellectual disabilities.

The Disability Survey will be run after the 2023 Census of Population and Dwellings. The survey always follows a census because census data is used to select and contact respondents. Around 23,000 adults and children, both disabled and non-disabled, will be interviewed for the survey.

**Below: Who's counting? – The Disability Survey is a once-in-10-year opportunity to know more about people with disabilities. Photograph by Sharon McCutcheon on Unsplash**





## SECTOR

# Physical restraint rules signal a new attitude

### **New rules about using physical restraint at school are a huge step in the right direction.**

Since changes were made to the Education and Training Act last year, schools can use physical restraint on students only when there are no other options to keep everyone safe.

To make sure there's no confusion about this, a group of advisors has been working on practical guidance for schools about when physical restraint can be used to better protect children and young people from harm.

IHC Advocate Shara Turner was a member of the Physical Restraint Advisory Group of parents and education sector and disability sector representatives working with the Ministry of Education. The group has come up with rules and guidelines that are now open for public feedback.

"I am hoping that they are useful and that they really shift attitudes," Shara says. "It's just about a shift in attitude from, that child is naughty, to that child has a disability-related behaviour and we should try to support them."

IHC wants these guidelines to be the first step towards having no physical restraint used in schools. Last year, in submissions on the law change, IHC Director of Advocacy Trish Grant called on the Government to move away from using force in schools towards de-escalation techniques.

"The Human Rights Commission has just published a report that identifies the alarmingly high rates of violence experienced

by disabled people. IHC has advocated for a specific lens on the violence people with intellectual/learning disability experience in their lives," Trish says. "Research evidence confirms that many people with intellectual disability fear speaking up about violence, abuse and neglect and the negative consequence of doing so.

"New Zealand has goals to eliminate restraint for adults held in places of detention. IHC has questioned why the same goal is not in place for disabled children and young people and asserts that in some cases the uses of restraint are examples of state-sanctioned violence."

Shara says it has been difficult to hear parents talk about the emotional impact of having a child restrained. "A child who is in a state to be restrained is in huge distress and is trying to tell you something."

She says it is smaller children who are more likely to be restrained; teachers are unwilling to intervene physically with older students. "You are 60 times more likely to be restrained in a special school."

Under changes recommended by the advisory group, schools must develop support plans for students who are at greater risk of physical restraint. Informed parental consent would be required if the use of physical restraint were attached to a child's support plan.

Schools would have to provide parents with a reasonable opportunity to attend a debrief after an incident when physical restraint has been used. Schools would be required to tell parents how the incident was managed in this debrief, rather than the initial

notification. This would make it easier for schools to notify parents/caregivers as soon as possible.

Physical restraint incident reports would have to state who reported the incident of physical restraint. This is to help show the extent to which staff using physical restraint are aware of their actions and their responsibility to report it. If a student has learning support needs, this information would help in monitoring the use of physical restraint involving this population. It would be an interim solution until physical restraint reporting can be linked to the standardised Learning Support Register.

The changes would allow future reporting through schools' student management systems to make the process simpler for schools.

All teachers and authorised staff members would have to complete online training in identifying stress triggers, understanding unmet needs and preventing, minimising and responding to student distress. The aim would be not to use physical restraint except as a last resort.

Teachers who are at higher risk of needing to use physical restraint, and all authorised staff members who are not teachers, would need to be trained in appropriate physical holds.

Submissions are open until 31 March 2022. Visit [consultation.education.govt.nz](https://consultation.education.govt.nz) – search 'physical restraint'.

**Above: A step in the right direction – IHC says the new physical restraint guidelines should be the first step towards having no physical restraint in schools. Photograph by Kuanish Reymbaev on Unsplash**





## SECTOR

# Young adult court removes barriers

**Young Porirua people charged with offences no longer have to stand in the dock while lawyers and judges use language they can't understand and make rules they are unable to follow.**

For the past two years Porirua District Court has been trying a new approach for young offenders designed to make their first court appearance also their last court appearance. This involves taking 18 to 25-year-olds out of the usual District Court and providing extra support to identify any health needs or disabilities they may have, adapting an approach used in the Youth Court.

The Young Adult List runs every Friday for people living in Porirua who have been

charged with offences committed in Porirua. It has been pioneered by Principal Youth Court Judge John Walker, who says many young people appearing in court have barriers that prevent them participating in the process. A high proportion of them have acquired brain injuries, intellectual disabilities, fetal alcohol spectrum disorder (FASD) or neurodevelopment disorders.

"How do we know who we are dealing with? The safest course is to assume that someone might have barriers," Judge Walker says.

British research has estimated that between 32 percent and 50 percent of its youth prison population have traumatic brain injuries and those rates are believed to be similar in New Zealand.

"We know that is the case. We know that from our Youth Court experience and the Family Court," Judge Walker says. He says these issues don't disappear when a young person reaches the age of 18. The presence of these disabilities, along with the fact that the young brain is still developing, requires special consideration.

Those appearing in the Young Adult List can access a range of wrap-around services similar to those available in the Youth Court, including specialist probation officers, adolescent mental health services, alcohol and other drug screening, and links to community support.

The idea is to make sure young adults can fully participate in the court process;





## ers to justice

can understand the various stages of the criminal process, for example, their bail conditions; and have the opportunity to be referred to the right support.

Judge Walker says one young man facing a raft of driving charges had a long history of driving without a licence. “The underlying cause of that is that he doesn’t have a licence. We are asking why he doesn’t have a licence. Sitting next to me on the bench is a report that he has FASD and intellectual disability and that is why he doesn’t have a licence.”

Support services swung into action and he was referred to an organisation that helped him get his licence. “He turned up eight weeks later with a restricted licence.”



*“People are terrified that they have made this mistake and their life is over.”*

Judge Walker says a person might not have a birth certificate and not know how to get one.

Dyslexia might be another underlying cause of why people breach court orders. In another case, a young man had been ordered to write a letter of apology to a victim, which he had failed to do.

Judge Walker asked him whether it might be easier to record a video apology on his phone. Which he did. Once his communication difficulties had come out in open court, the forensic nurses attending the Friday court were able to confirm that the young man was illiterate.

The Young Adult List plans to adopt a disability screening tool, which will help determine what issues are in play. An Australian online screening tool for assessing levels of disability had been considered but wasn’t the right fit for New Zealand. Work is being done to find a better one.

Judge Walker says that in the meantime those involved in the Young Adult List are using their experience to detect disabilities and make sure people can follow the process. Information from the Youth Court

and Family Court is shared and training is being offered to increase knowledge of, for example, acquired brain injury.

This Friday court drops the legal jargon. “We have nothing to lose by dropping formality, using plain language, involving whānau. We do no harm by removing those barriers,” Judge Walker says.

He doesn’t want to see families left to watch at the back of the court. “We actually do want to hear from them. They are certainly not to feel shut out. They need to be talking to the court, talking to the police, talking to lawyers. Certainly at Porirua we would be welcoming that with open arms.”

Louise Brown, the Duty Lawyer Supervisor at Porirua District Court, has played a key role in developing the Young Adult List court pilot. “I love it. I really do. Fridays are my favourite day.”

Louise came to law from a background in sociology and education and says she feels lucky to have a job that pulls together all her experience. “I have come into my career firmly believing in rehabilitation. I believe firmly in this court. I do believe it’s making a difference, and it’s about the future.”

In teaching, “if you can reach one out of 100 you have achieved something, and we are doing better than that”, she says. “That is why I love it. I love it that there are issues here that we can answer.

“I am simplifying the language all the time. I am simplifying the bail conditions all the time. If they don’t understand, then I go back to the point where I lost them.”

And it is about changing the course of events for a young person. “I have seen it over and over. People are terrified that they have made this mistake and their life is over.”

The Young Adult List takes a bit longer to work through the legal process, but Louise sees that as an investment in the future. “You stop and take the time to understand what is going on with them,” she says. “That is why we take time because the young person has to earn the outcomes.

“A lot of the time defendants feel good that they have achieved. When they get there, there’s a lot of pride, achievement, relief.”

The Young Adult List, which ran as a pilot project from March 2020 to February 2021, has now become business as usual in Porirua. With the success of the project, the Young Adult List will be extended to Gisborne in March, followed by Hamilton.

**Left: Pioneer – Principal Youth Court Judge John Walker launches the Young Adult List pilot project at Porirua District Court.**

**Above: A way back – Louise Brown, the Duty Lawyer Supervisor at Porirua District Court, believes the initiative is changing lives.**





## SECTOR

# Patrick has the fight of

**Patrick Williams had always slept well, until that night in May last year when he couldn't sleep at all. His parents Julie-Ann and Raymond didn't know what the problem was.**

"Eventually he said, 'It's sore. I can't lie on my side,'" Julie-Ann says. "He showed me this half-tennis-ball-size lump in his groin."

Patrick was in hospital that night and the next day the family was given the diagnosis. "We had a meeting with the doctor, and he said it is looking like testicular cancer that has spread," she says.

By the time Patrick was diagnosed he had stage 4 cancer, and Julie-Ann blamed herself for not knowing what was going on. "In those first few weeks it was pretty awful thinking why did I not consider this? Why did I not think of this? It was a good couple of weeks blaming myself and then you just roll on with it."

She says because Patrick, who has global developmental delay, can shower himself, they had no way of knowing about the lump.

"His tumours spread quickly through his lymphatic system. It was very fast-growing. There was no pain either, there was just a mass," Julie-Ann says. "It didn't bother him. He just couldn't get to sleep."

"Within 10 days he had surgery. They took the right testicle out."

Patrick, who was then 16, faced three months of chemotherapy and two rounds of surgery between May and October. The October surgery was a seven-hour marathon as surgeons took out lymph glands throughout his abdomen.

Patrick lost a great deal of weight but came through it bravely. Julie-Ann says he will cope with most things if his parents are there with him.







# his life

“In February he has risky cardiothoracic surgery. They will collapse one of his lungs and they will take out the tumours around the back of his trachea and take out tumours on the external part of his lungs,” Julie-Ann says.

But the family, from Charing Cross west of Christchurch, asked for a holiday together first. In January they took the break they were determined to have – two weeks at a cabin in Kaiteriteri – along with Patrick’s older sister Sophie, 19, and younger brother Sebastian, 15.

As well as global development delay, Patrick has a condition called pica, where people eat non-food items. “He would eat sand, potting mix, shaving foam and paper, and anything,” Julie-Ann says. But it gave them a lighter moment at the start of their holiday. At the camping ground, Patrick was handed the slip of paper with the wifi password, and by

the time they got to the cabin it had been eaten. Patrick, who also has a great sense of humour, was sent back to the desk for another one.

The experience has left Julie-Ann passionate about warning parents with disabled sons to be on the look-out for testicular cancer. But she acknowledges this might be an awkward subject to raise with adolescent boys. “We were shocked when we were informed that lumps can start from the age of 11.

“My husband and I have been impressed with the education that Patrick and his classmates have received over the years around cleanliness, public and private parts and communication with the opposite sex.” However, they did not think the topic of checking for lumps and bumps was discussed. “I am really concerned that all lads are aware of what requires attention in this department. A full explanation of what it

is is probably what they need,” she says.

“I want to shout out to anyone with boys or men with a disability to get them checked.”

**Top left: Time out – Two weeks at a cabin in Kaiteriteri was just what the Williams family needed; (from left) Sebastian, Julie-Ann, Patrick, Raymond and Sophie.**

**Left: The long haul – Patrick had three months of chemotherapy and two rounds of surgery last year.**

**Above: Playing favourites – Patrick’s collection of 28 Thomas & Friends trains and tracks even went on holiday with him to Kaiteriteri. During his weeks having chemotherapy he would research the Toyworld website for his next bravery reward, then on the way home they would go shopping.**

# Kiwi Tarp fixers keep the show on the road

**The next time you are sitting behind a big rig on the highway, take a look at the tarpaulin covering its load. It might be a Kiwi Tarp, held together thanks to the hard work of Brittany and Anthony.**

Brittany Hoyle from Maungaturoto, a small Northland town, has just landed a permanent job with Kiwi Tarp, a manufacturer of retractable truck tarpaulins. She started with the company on work experience in 2020, and has become an essential part of the team, putting together hardware and bolt kits for the guys out on the road installing the truck tarpaulins.

Kiwi Tarp is part of the CPL Group based in Kaiwaka, and Director Bernie Stewart says they were aware that Brittany, who has Down syndrome, was close to finishing school and got in touch with her parents. Bernie has a sister-in-law of a similar age to Brittany with Down syndrome and was aware that finding work was not going to be easy for her.

It came at exactly the right time for Brittany. At 19 she is the youngest of 12 in the Hoyle family, and with the recent weddings of two sisters, she was the last one at home with mum and dad. "She is now a proud aunty, 19 times over," says her mum, Sherilyn Hoyle.

Sherilyn says it was the right decision for Brittany to do work experience for the last year of school. Brittany can be anxious, and without that experience she wouldn't have been ready for work.

"Our main focus for her is life skills," Sherilyn says. Brittany loves it and is very excited about going to work, and is now transitioning to employment. She says the work environment has really helped Brittany's social skills.

Lockdown upset her routine for a while, but working from home wasn't the same. "Over lockdown we had to stay at home," Bernie says. "We said to her parents, we can get her a lot of boxes. But they said it would take away the importance of going to work."

Brittany reports to the CPL Production Manager and, until she left school at the end of last year, turned up with a teacher aide.

Bernie says the tarp installers go out on the road to work on trucks in yards all over the country, and no longer have to sort through a box of fastenings to find the ones they need. Brittany is responsible for counting out the correct fastenings into kits for easy access.

"The installers absolutely love it," Bernie says. "Brittany is responsible for the tarps staying on the trucks."



At the same time, further south in Levin, Bernie's brother Reuben Stewart has got in on the act. Reuben supervises the company's installations in the lower North Island and South Island and realised they needed their team player too.

Reuben contacted IHC and was put in touch with the Dennill family. Anthony Dennill, 20, started work experience in November cutting cables and packing up hardware kits. He also prepares the bolt kits that go inside each hardware kit with all the small bits and pieces. There are 50 components in each kit.

"He is doing an excellent job. Our boys take one kit for every job, so it's probably five or six kits every day getting used," Reuben says.

He says it's a safeguard for the installers and prevents any hold-ups on site. He says it's very costly for a truck to be off the road, even for half a day.

Leonette Dennill, Anthony's mum, says he used to follow a checklist to make sure all the components were included, but he can now do it from memory. "It's actually perfect. I go with him every day, but when school starts one of his teacher aides will be going with him. He would like that to be his job for always."

**Above: A good fit – Brittany Hoyle's work experience with Kiwi Tarp has boosted her confidence.**

**Right: Part of the team – Anthony Dennill has found the job he wants and the team he likes at CPL in Levin.**





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IHC

# Who cares for the carers?

## Who cares for the carers? The people who do the best job are those walking in the same shoes.

IHC's i-Volunteer programme has tapped into a largely silent group of people – the family carers – and found people looking for connection and friendship.

i-Volunteer is a one-to-one friendship programme that links people with intellectual disabilities and family carers with friends who they can connect with online or by phone.

i-Volunteer was launched a year ago, after the 2020 lockdown, to connect with disabled people online when face-to-face catch-ups weren't possible. It turned out there was often a carer who could do with a friend too. And, in a nice coincidence, some of the people prepared to step up and offer that support have been other carers.

## Linda Seto

In Auckland Linda Seto needed a bit of extra time to settle her 14-year-old daughter Abbey into high school. Abbey has autism and very high needs. So Linda, who had been delivering Meals on Wheels for Red Cross, freed up some hours. Then in June last year she decided she had some time to devote to volunteering with IHC.

"I felt the i-Volunteer role would allow greater flexibility to fit around my family commitments," she says.

Linda says she jumped at the opportunity to encourage another carer. "I just really know what it's like. I can understand – the energy, the time it takes to advocate for the child. The parents and the carers of these special children go through these different emotions because there's a lot going on."

She has connected online with a mother

parenting her disabled boy on her own.

"Our friendship is based on a mutual respect for each other. We have some lovely chats about our everyday happenings. My daughter and her son had a lovely chat one day. I enjoy hearing about her son's achievements. To us as parents of special needs children it means a lot that our children are meeting milestones. It's these little challenges that they overcome. I just enjoy hearing about all the feelgood moments," she says.

"I want to give back to the community and to serve the community. Also, I have family with disabilities – my daughter [Abbey] and my brother."

Linda's brother Philip, 49, lives in Taupo. He has an intellectual disability. She has a younger daughter, Danielle, who is 10. "We have quite a busy life in Auckland.





In Auckland, Dalene joined the IHC face-to-face friendship programme, but when her husband got a permanent job in Masterton towards the end of last year, Dalene made the transition to the i-Volunteer programme, which meant she could continue to volunteer online.

She connects with a carer who also has a disabled son. “Chatting to other mothers of disabled children gives one a fresh perspective. We could brainstorm about her situation too and exchange ideas. Our virtual friendship goes beyond our having disabled children. Chats with her leave me feeling more energised and positive about my own situation.” she says.

“Our son has global developmental delay. He was diagnosed at the age of one. His development is very slow. Having a child with an impairment is challenging and can be very lonely. When you close your door at the end of the day you remain in the same situation; I think this is hard for people with normal families to fully comprehend.

“I get immense personal satisfaction from being of service and supporting those in need.”

IHC National Manager of Volunteering and Community Development, Sue Kobar, says during COVID-19 lockdowns IHC needed to rethink how it connected with the people it cared about.

“Caring for a family/whānau member or a friend can really affect a person’s ability to socialise, limiting their connections to support. Having a friend to chat to regularly can have a positive impact on a carer’s life.”

If you would like to find out more about the i-Volunteer programme or would like to sign up, head to the Volunteering page of our website, call 0800 442 311 or email [volunteering@ihc.org.nz](mailto:volunteering@ihc.org.nz). IHC welcomes applicants aged 17 and over from anywhere in New Zealand.

**Left: Sharing lives – Linda Seto, with daughter Abbey, enjoys celebrating milestones with another family.**

**Below: Fresh perspective – Dalene van der Leek enjoys brainstorming and swapping ideas with a carer about their children.**

I just really enjoy being a mum, but it does have its challenges with Abbey.” She says there were a lot of upsets in 2020 with Abbey’s transition to high school, but Abbey did a lot better last year. “She is a little bit calmer and more settled.”

Finding herself in an easier space, Linda wanted to reach out to another family. “I just wanted to be part of a service that supports families to cope,” she says. “I feel like I am contributing to the wider community.”

## Dalene van der Leek

Dalene van der Leek emigrated from South Africa in 2019 with her family. They came from Mbombela (formerly Nelspruit) in the north near the Kruger National Park. Volunteering for her was a way to connect to a new country. “We were fortunate to have arrived in New Zealand about two months before the first COVID lockdown. Being a stranger in a new country I soon realised the value of the support network I had back in South Africa, how much I missed and longed for it. I wondered how I could make a difference by getting involved.

“We have a disabled son ourselves and I felt that it would be very rewarding to support someone.”





# It took six weeks for Courtney to make the team

**Courtney Ratana has his first job at the age of 40. He started in January as a pool attendant at the Lido Aquatic Centre in Palmerston North.**

He works there every Monday. "I have got a top and I have got a badge," he says. Both are important to Courtney because they identify him as a member of the Lido team. He will be paid and there is every chance and every hope that his hours will increase.

The Lido is the perfect workplace for Courtney, who is a keen swimmer and a regular in the pool. His job has been the start of huge life changes – he is about to move out of home and into a flat.

Courtney joined the staff after completing a six-week internship developed by Choices NZ Life Coach Robyn Poole in conjunction with the Palmerston North City Council and Lido Aquatic Centre. He worked for two hours every Monday on a structured work experience programme designed to familiarise him with not just the job, but being in a work environment.

He started with a walk around saying hello to pool staff, followed by regular cleaning duties involving wiping down tables and the lids of rubbish bins, cleaning the glass in the sauna and steam room and wiping down the lockers.

Courtney then helped wherever he was needed, sometimes hosing the pool complex, vacuuming, or sweeping up leaves.

Robyn mentored Courtney during the internship, along with Lido Aquatics Coordinator TJ Lyne-Lewis. Robyn says there have been huge benefits for Courtney in terms of his social skills, work ethic, mental health and timekeeping.

"They really enjoy having him around. Even on his days off, he comes in and says hi. His work ethic is amazing. When he was asked to wipe the glass in the sauna and the steam room, he started to go around and wipe all



the glass in the facility. He goes the extra mile," Robyn says.

The first two weeks were a big ask for someone who had never been an employee. But Courtney picked up the job quickly and now has a new watch that helps with timekeeping.

TJ says Courtney was shy to begin with. "For the first two sessions Robyn was certainly essential, but for the next four sessions Robyn was with me in my office and Courtney was working independently." TJ says Courtney is very excited about his job. "He is very happy; his confidence has gone through the roof."

Choices NZ Manager Jo Barsanti says Courtney told her that getting the job was

one of the best things that had happened to him. "He said, 'This is like a dream!'"

She says the internship is being repeated this year with another intern. The Lido is keen to go again. "They were the ones who said to Robyn, 'We are doing this again, aren't we?'"

Choices NZ provides flexible disability services to individuals through its facilitator and life-coaching services.

**Above: First job at 40 – Courtney Ratana, with Lido Aquatics Coordinator TJ Lyne-Lewis, talk through the cleaning schedule.**



Continued from page 5.

“I was determined to have another child, but Richard was hesitant.

“I definitely felt I was taking a risk having another child.” Her third child Kyle was not affected. He is now at medical school and agrees that his choice of career may have something to do with the health issues faced by the family.

The same question about whether the disability might be inherited was faced by their daughter Sophie when it was her turn to have a family.

“My daughter is 25 and she had twins two and a half years ago. We were adamant that she was going to get tested. She had an amnio [amniocentesis – a test for a genetic or chromosomal condition],” Nicola says. Her granddaughter is named Zahra and grandson is Kais – “vibrant and very healthy children”.

Kyle says that having a diagnosis for Luke has not made any difference to him in terms of treatment, but it has answered other questions about life expectancy and what symptoms are related to the genetic condition. “There is a lot of power in knowing something, even if you can’t do anything about it,” he says.

What they now know is that the genetic change in the *DYRK1A* gene was not inherited in Luke’s case. “It’s called a first-generation mutation. It’s random,” Nicola says.

“I am deeply grateful because to get a genome [sequence and analysis] done is very, very costly.”

Nicola says Luke is limited in what he can do. “He can’t shower himself. He is allowed to go to a day programme, but only for two days. He loves the Sky Tower, he loves walking – he can walk 10 kilometres easily. He had a fantastic 21st.”

These days Nicola does her best to help other people to understand what it’s like, including talking to trainee nurses about her experiences with Luke.

“Don’t think it can’t happen to you,” she says. “Life is not over, and you just have to do the best you can.

“I would love to help any women in any way. It’s so hard, those first years. It’s so lonely,” she says.

But looking back, she is grateful for the support of her family.

“This has happened. You can either sink or swim, and you have to do your best to swim.

“You look at what you have achieved over 21 years and what you have achieved as a family. It’s hard though.”

University of Auckland researcher Dr Jessie Jacobsen leads the research project alongside Associate Professor Klaus Lehnert, Professor Russell Snell, and PhD student Chris Samson. They worked with colleagues at Massachusetts General Hospital and



Harvard Medical School in Boston to resolve the complexities of the specific type of genetic rearrangement (a balanced rearrangement) observed in Luke’s DNA.

Jessie says one of the things that drives her is being able to provide answers for families. She says it is often harder to have a medical impact or intervention when a child is older, but even with older children, having a diagnosis gives the families an idea of what they can expect.

She says a balanced chromosomal rearrangement is a bit like rearranged chapters in books. “A balanced rearrangement is when you have whole chapters missing from one book (chromosome), but they reappear in another book (chromosome). As we don’t lose many of the words, just rearrange them, we often call this a balanced structural variant.”

Her research has been funded by the IHC Foundation. In the pilot project, from 2016 to 2018, the team conducted research with 20 families and was able to find the genes and mutations responsible for rare conditions in 14 children.

A second project, now nearly completed, aims, first of all, to provide answers for families to help manage the condition. Second, the results from these families could contribute significantly to evidence to support the use of this technology in mainstream clinical use. Third, the gathering and cataloguing of naturally occurring genetic variations in the population will allow for a more efficient approach to identifying those genes that cause rare disorders.

“We are very grateful to the IHC Foundation for its help to help these families,” Jessie says.

**Above: Certainty – The Sterne family is relieved to have some answers (from left) Patricia Alston (Luke’s grandma), Zahra, Nicola, Kyle, Luke, Sophie, and Richard holding Kais.**

**Below: Sink or swim – These days Nicola does her best to help other people to understand what it’s like to support Luke.**







IHC

## A little kindness has gone a long way

**IHC Association member Doreen Barns wondered what had happened when she had a call just before Christmas from a reporter from the *Whanganui Chronicle*.**

But it was far from bad news. Doreen had been named the *Whanganui Chronicle* Person of the Year for 2021 for bringing some joy into the lives of local people with intellectual disabilities. "It was amazing. I felt quite honoured, but it wasn't all my own work," she says.

That seems to be part of her success. She motivates people to help her make things happen.

Doreen is a member of the IHC Whanganui Association and for the past two years has been its Events Coordinator. With COVID lockdowns, the challenge has been to make sure people with intellectual disabilities have had something to look forward to.

The monthly disco and pizza nights were disrupted but people were still able to attend tribute concerts at the Royal Whanganui Opera House, featuring the songs of Neil Diamond, the Bee Gees and Abba. Doreen also organised a screening of the film *Poppy*, where filmgoers were able to meet the star of the movie, Libby Hunsdale, a Whanganui local.

The real challenge came at Christmas, with the cancellation of the IDEA Services Christmas function. It was an idea from Doreen's daughter Hayley that help to save the day. Hayley, 43, who has an intellectual disability, lives at home.

"Hayley likes to collect soft toys and she loves them." Hayley and Doreen had gone to visit a friend in hospital and the soft toy Hayley had taken as a gift had been very warmly received. It gave Doreen the idea of delivering a personalised Christmas teddy to everyone in IDEA Services.

"I sourced them through Farmers and I said, 'Can I have 100 teddies and can we have them for \$20 each?'" Each of them had the person's name sewn on by the Whanganui Sewing Centre and they were delivered along with a special Christmas lunch by former Whanganui Grand Hotel owner Neville Gorrie in his 1954 London Transport double-decker bus.

"I rang him up and asked him if he would be our Santa and drive the bus. We delivered them over three days." The Christmas meals of roast lamb with mint sauce, ham with cranberry pickle, potato salad and couscous salad were provided in takeaway containers by restaurateur Dibin Paul from the Brick House.

"The look on their faces was just amazing, that they had a teddy, or a toy, or even a gift from somebody." Doreen encourages everyone to cuddle a teddy sometime. "If you do get a teddy and put it right up to your neck and give it a cuddle, it's amazing."

She is uncomfortable with being the focus of so much good will. "It's not just me. Support from the committee is wonderful."

IHC Whanganui Association Chair Nerrily Frith says Doreen is an ideas person. "We talk about what we want to achieve in our committee meetings and when she gets an idea it's all go, and we all have to run to keep up."

"We are so proud of Doreen and indeed our whole committee for the commitment made to support our clients over a difficult time. We got our double-decker bus and we all delivered the meals and teddy bears to all the houses in Whanganui. I must say that we all had a few tears along with our clients when they saw the teddy. All staff working that day also received a meal."

**Above: Ideas person – Doreen Barns knows how to make good things happen. Photograph: *Whanganui Chronicle***





IHC

# Friends in high places

**No matter where you live in the country, you have some friends in high places in Wellington.**

The team in the IHC Library on the 14th floor of a Willis Street building is ready to connect with anyone with a question about intellectual disability, autism or other developmental disability.

Until recently the librarians have been voices on a phone or names on an email. But lockdowns have brought them into the limelight of Facebook interviews.

It's hard for librarians to connect with people who have diagnoses of intellectual or development disability because of privacy around health. This can be overcome to an extent by the online platforms.

"That is the advantage of using a platform like that. You can present yourselves," says Phil Clarke, Head of Library and Information Resourcing at IHC.

He and Reference Librarian Ros Booker appear in interviews filmed for Awhi Ngā Mātua, a Facebook community for parents of tamariki with disabilities and high health needs, supported by IHC.

"Awhi Ngā Mātua is a huge benefit to us. There are a whole lot of people we haven't connected with before. A couple of thousand people read that page," Phil says.

Ros and Phil cover topics that are on the minds of the families who connect with Awhi. Regular emails also go to IHC Library members, answering questions and with news about the latest resources.

Phil says there is a big demand for resources covering autism and the various life stages – toileting, transitions to and through school. "Anxiety is always a huge issue. Puberty is a

huge topic [and] behavioural resources," he says. "Approach us with a question and we will go from there. You don't need to be a member of the library or a member of IHC."

Phil wants to give people information in the format that work best for them. "We used to lend DVDs quite regularly to people. They go online now. Most people don't have a DVD player.

"Anyone with a question about intellectual disability has an almost unimaginable pool of information they can access online, but finding authoritative, high-quality information isn't easy. At the same time as we've become so information rich, we're limited in the amount of time we have to find, read and analyse that information and that means the IHC Library is even more important now," Phil says.

"There will always be a demand for books and paper resources, but I think the demand will be for information in different ways for different people. We will be summarising and packaging that information more and presenting it in different ways. With Awhi, parents are talking to each other and exchanging information about resources. Another potential resource is apps – what are the best apps out there?"

It's easy to talk to the librarians and borrow resources. Books, articles, videos, e-books and games can all be accessed for free – the only cost is the return postage to the library.

First join the library, either online at [ihc.org.nz/library-page](http://ihc.org.nz/library-page) or by calling 0800 442 442 (extension 42492), or email [librarian@ihc.org.nz](mailto:librarian@ihc.org.nz)

**Above: Just ask – You don't need to be in Wellington to ask Phil Clarke and his team a question.**

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If you have a question  
you can't answer, try us.

The IHC Library is free to use and open to anyone living in New Zealand. We have information on all aspects of intellectual disability, autism and other developmental disabilities.

Email us at [librarian@ihc.org.nz](mailto:librarian@ihc.org.nz) or phone 0800 442 442.

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