

# Community MOVES



**FLYING WITH  
CHARLIE**

**YOU HURT MY  
BROTHER'S HEART**

**TIME TO HEAL**

**LIBBY LANDS THE  
LEAD ROLE**

# Personally speaking

In our first IHC Board meeting each year we allocate time to our long-term strategy, to tracking our progress and considering our priorities for the next 12 months.

This year it is inevitable that much discussion will focus on our response to people's changing expectations and how we, as the IHC Group, respond to the chronic underfunding of disability services and lack of housing for people in need. This will be no easy task. Leadership from government has been lacking for many years and without the sectors driving a coherent agenda we will likely see more politics than progress in this election year.

Our senior staff serve on boards and on disability sector and government working groups. Using our connections, our strength and our expertise, we advocate for better lives for people with intellectual disabilities, which has been a fundamental principle of IHC for our entire 70-year history. Housing need and wider disability issues have direct impacts on people with intellectual disabilities and, along with providing disability and housing services, we advocate in these areas.

Each election year we run focus groups and candidate events in order to give people an opportunity to tell us their most crucial issues and to question political candidates directly. As one of New Zealand's major non-government social housing providers we will also be surveying our tenants to ensure we are advocating and helping highlight the issues they consider most important.

We know that many families find accessing the right information, support and services incredibly challenging. This year our Annual Appeal centres on a family struggling to get the right support for their child who, without a formal diagnosis, was slipping further behind and becoming more isolated at his school. Our local IHC Family-Whanāu liaison was key in turning that child's life around.

While it's important to make sure we are standing up for people with intellectual disabilities nationally and internationally, it's equally important to recognise the impact we can have on individuals and their families. I'd like to personally thank the many of you who are so generous in your support.

Ralph Jones  
IHC Group Chief Executive



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# Sister pleads for tolerance after neighbours throw rocks

An assault on her young brother upset a Te Awamutu woman so much she wrote to her local newspaper urging the community to show some understanding of people with autism.

Rhiannon Venk says neighbours threw rocks and hosed nine-year-old Ronan Cavanagh, who is hooked on collecting wheelie bins from up and down Frontier Road.

In a letter to the *Te Awamutu Courier* late last year, she described how Ronan had come home crying with large bruises on his legs, and then in a separate incident had water squirted at him as though he was a stray dog.

“Due to his disability and due to his behaviour and due to his own little world, I am 100 percent confident that he will never ever understand why grown men and women, who should be role models and trusted, would throw rocks at him or blast water when he enters their property to touch their bin,” she wrote.

“You hurt my little brother’s heart today. And he doesn’t understand what he did wrong.”

Rhiannon says she wants people to realise that Ronan is not being naughty when he collects the bins.

“He absolutely loves wheelie bins,” says Mum Nicole. “He will go for miles to find a kind we don’t have. He likes to rearrange them and make sure that the neighbours have the correct stuff in their recycling bins.”

Two years ago, the family did a letterbox drop to neighbours to explain that Ronan has autism and to ask them to be patient if they found their bins were missing. They asked them to put their street numbers on the bins so the family could return them.



Rhiannon Venk and her brother Ronan Cavanagh with a few of his favourite things – the Frontier Road wheelie bins.

“We did that straightaway when it started becoming quite an issue. Some mornings I would wake up and have 20 bins on my property and I would have to try to find out where the bins came from. He has been playing with the bins since he was about two. But tolerance is wearing thin with quite a few of the neighbours.”

Rhiannon says Ronan was able to identify the houses where he had been assaulted, but enquiries by Police had not got to the bottom of what happened.

Ronan hasn’t stopped collecting bins on recycling days, but now avoids the area where he was assaulted and collects them from the opposite side of the road. He has also shifted his focus to the man who collects the rubbish bags.

“Wednesday is a huge day for us,” Rhiannon says. “He was outside this Wednesday from daybreak to sunset waiting for Matt.”

She hopes that 2020 will bring more understanding of Ronan and people with autism.

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**COVER IMAGE:**

**Charlie and Betsy Ussher and Bugs Bunny at Warner Bros. Movie World on Queensland's Gold Coast. See story page 5.**



New tenant Raymond Holloway, Gate Pā resident Teisha Paratene and Associate Housing Minister Kris Faafoi celebrate the opening of six new houses in Tauranga.

## Six new homes may be the first of many for Tauranga

IHC Group’s property company, Accessible Properties, has opened six new homes in Tauranga for people struggling to find housing.

Associate Housing Minister Kris Faafoi cut the ribbon on the new development at 878 Cameron Road.

The homes are part of Accessible Properties’ plans to help address the Tauranga housing shortage, and the Minister was singing its praises.

“I welcome Accessible Properties’ latest contribution to deal with New Zealand’s housing shortage, and I acknowledge all the individuals, organisations and communities who have stepped up to respond,” Minister Faafoi said at the ceremony.

New tenant Raymond Holloway was pleased to finally see his home, which he had watched being built from his previous accommodation across the road.

The former serviceman, who is deaf, told *The Bay of Plenty Times*: “It’s a new lease on life.”

Accessible Properties Chief Executive Greg Orchard says the aim of the Cameron Road development is to create great-looking homes that also meet the demand and needs of the community.

“We know that we need a community-wide, multifaceted approach with great engagement with all the players involved in making places work,” says Greg.

It’s all part of Accessible Properties’ commitment to the region. Accessible Properties wants to replace 140 former state homes in Tauranga with more than 400 new townhouses and apartments.

Greg says housing wellbeing has become an urgent issue for Tauranga and the Western Bay of Plenty, and Accessible Properties is taking action. “We think we can make a real difference to this community, which has become one of the most unaffordable places to live in the country.”

The ambition is to increase new supply by at least 300 homes within 10 years, which would deliver a 26 percent increase in the organisation’s housing stock.

“We want to see a master planning



Raymond Holloway is finally inside his new place, which he watched being built.

approach – a diverse range of housing types overlooking the street and shared communal areas,” Greg says. “In addition, we are continually working to improve the quality of the housing we provide to tenants.”

Accessible Properties is also an important partner to IDEA Services and the people we support. In the past year, Accessible Properties has worked closely with IDEA Services to supply new properties or to modify properties to meet people’s changing needs and expectations.

Accessible Properties also completed 40 development or modification projects on properties used by IDEA Services or tenanted by individuals eligible for Supported Living.

# Flying with the boy who loves Thunderbirds

Charlie Ussher loves the TV animation show *Thunderbirds* so much that he fantasises that a plane he is travelling in will explode and Virgil Tracy will come to the rescue in Thunderbird 2.

But talking about aircraft exploding and bombs going off is a high-risk activity when you are travelling by plane, and high stress for Charlie's parents Lisa and Mark.

Last year the family flew to Australia's Sunshine Coast to visit Charlie's grandfather and the theme parks. Lisa says she had been talking about the trip to see her Dad for three or four years, but they had to wait for 11-year-old Charlie to get over his preoccupation with explosions and other issues relating to his autism. "His whole world is space and aircraft and *Thunderbirds*," Lisa says.

"We were concerned that he would have a meltdown on the plane. But we were mainly concerned that because of his love of *Thunderbirds*, he wanted our plane to blow up so the Thunderbirds would come and rescue us."

But after talking to a lot of people about their travel strategies and arming themselves with rescue lollies to be eaten when Charlie felt scared, they headed to Australia in July. They booked the same airline both ways, and the same seats, because Charlie always likes to follow the same path home.

Charlie also tends to run when he is stressed, and at Brisbane Airport Lisa and Mark faced their biggest hurdle. An immigration officer decided that Charlie should be the first to go through the face scanner at passport control. Lisa says they tried to explain that either she or Mark should go first in case



Charlie Ussher at Sea World on his family holiday to Queensland.

Charlie decided to run. But the officer wouldn't budge. In the end Charlie's sister Betsy, aged seven, went first and it was her job to manage her brother. Lisa says they told Betsy that if Charlie ran, she was to run with him.

Mark says he got to the point where he decided that if Charlie ran, the airport would have to handle it. "I was pretty angry."

Lisa says as it turned out "both of them were standing there waiting for us".

In September last year Melbourne Airport launched a Hidden Disability Programme at its international terminal to support travellers needing special assistance. It was the first Australian airport to introduce the programme for travellers with autism, anxiety issues, mental health conditions, dementia, and

visual and hearing impairments. Travellers can request a lanyard to wear through the airport from check-in to departure to allow airport staff to recognise that they may need extra help.

A sensory map is available, which identifies high-sensory and low-sensory areas. This is to help travellers prepare for additional noise and crowded areas and to find quieter areas.

The airport website provides 'social stories' to walk passengers through the international departures and international arrivals processes in an easy-to-understand format. Melbourne Airport staff will all be trained in the Hidden Disability Programme.

Lisa says the Hidden Disability Programme at Melbourne Airport is good news and would have been very helpful for the family.



Libby Hunsdale is spending her summer preparing for her role in new feature film *Poppy*.

# Libby lands the leading role

Young Whanganui actor Libby Hunsdale is to play a role close to her heart in the feature film *Poppy*, being made on the Kāpiti Coast north of Wellington.

*Poppy* is a story about falling in love, learning to drive and entering the local car burnout competition, and Libby is getting primed for her role with some hands-on experience at Whanganui's Midtown Motors.

Garage owners Raj Patel and Janine Chalk were happy to let Libby shadow their apprentice Jon Morrison before she headed south for filming. Libby's grandfather, well-known local stock-car driver Ormie Andrews, had a long association with the garage. He was a member of the Wanganui Warriors Superstock Team.

Libby, 18, a student at Whanganui Girls' College, was cast for the leading role of Poppy after a nationwide search. She lives with her grandmother Barbara Andrews, who saw an article in a Sunday

newspaper saying the filmmakers were looking for a girl with Down syndrome who was ready to tackle anything. Libby impressed writer/director Linda Niccol (*Second-Hand Wedding*) with her vivacious personality and ability to deliver a performance. "Libby is a real find. She embodies the spirit of Poppy. She's a true performer," Linda says.

*Poppy* is the story of a young woman with Down syndrome who wants the same opportunities as others her age. She takes matters into her own hands when her over-protective brother holds her back from achieving her ambition to become a motor mechanic.

Libby says she's over the moon to be cast and she already feels a connection with the character. "What I love about Poppy is that she's ambitious and wants a career. I do too. Poppy doesn't care about what people think of her and the fact she has Down syndrome. I really relate to Poppy. We could be sisters," says Libby.

Barbara says Libby has studied drama and dance and has been

in shows. "But the camera is something different," she says.

The IHC Foundation has contributed \$25,000 to provide acting coaching for Libby. This will involve performance-related workshops, rehearsals with other key actors and one-on-one coaching with Miranda Harcourt. Miranda has worked as an acting coach all over the world, with stars including Nicole Kidman, Reese Witherspoon and Kiwi actor and comedian Rhys Darby.

Miranda Harcourt says *Poppy* is a story firmly centred in the world of self-determination. "She is a wonderful character leading a unique and wonderful story."

The Poppy Pictures production is being supported by the New Zealand Film Commission, with funding from the 125 Fund created to celebrate the anniversary of women's suffrage. It is also supported by NZ on Air alongside private supporters and sponsors. TVNZ will screen the film in New Zealand.

# 'I might be the first – I don't want to be the last'



Sir Robert Martin KNZM – one of New Zealand's newest knights and disability activist.

When he returns to the United Nations in New York next month, Sir Robert Martin will carry his country's highest honour. He was made a Knight Companion of the New Zealand Order of Merit in the New Year Honours for services to people with disabilities.

It's another first for him. He is the first New Zealander with an intellectual disability to be knighted. He was also the first to be elected to a UN Human Rights Treaty Body in 2017, and the first to chair a meeting within a UN session in 2018.

"I might be the first person with an intellectual disability, but I don't want to be the last. It seems that I am the first person to do this and to do that, but for me it's making a way for other people to follow," Sir Robert says.

"I was extremely humbled. It's not for me, it's for people with disabilities who got me where I am and the people who assisted me over the years," he says. "I couldn't

have done it without the help of People First and IHC.

"It's also for the people who are not with us, who never got a chance to tell their stories."

Sir Robert, who is married to Lynda and lives in Whanganui, says he still feels the presence of the people who he lived with in some of New Zealand's grimmest institutions. "I do because those people are really important to me. I have never forgotten my roots."

In November he gave evidence to the Royal Commission of Inquiry into Abuse in Care about his own experiences of abuse and how he was made to feel he was nobody.

Sir Robert says he regards education as one of the major issues facing people with intellectual disabilities and he is right behind IHC's work in this area. "People are still falling through gaps. Education is not a feel-good thing; it's a basic human right. Everybody has a right to an education – to be assisted to be who they can be."

He says disabled people need to take their place in the world and show what they are capable of.

## Honour for IHC patron

Lady Gillian Deane was made a Companion of the New Zealand Order of Merit for services to philanthropy, particularly for rare disorders, the arts and youth. Lady Deane is a Patron of IHC New Zealand with her husband Sir Roderick Deane.

"Still people are invisible around the world. I often ask, where are the people with learning disabilities?"

Sir Robert has been involved with the self-advocacy movement for people with learning disabilities for more than 30 years. He is a Life Member of People First New Zealand Ngā Tāngata Tuatahi, the national disabled persons organisation, originally set up by IHC.

He is serving a four-year term as an independent expert on the UN Committee on the Rights of Persons with Disabilities and plans to stand for re-election this year. Sir Robert has held roles within Inclusion International and was National Self Advocacy Advisor and Trainer for IHC New Zealand between 1991 and 2010.

# Early Christmas getaway was the

Just before Christmas Suzanne and Chris Leigh had their first break away together in a long while. It wasn't for long – one Saturday night away. And they didn't go far – just across town.

“I thought I just need to do the easiest thing at the moment,” Suzanne says.

Suzanne was diagnosed with breast cancer in 2017 and there have been many rounds of treatment since the cancer spread to her sternum, pelvis and back.

The Christchurch couple stayed a night at Peppers Clearwater Resort through IHC's 'Take a break with us' programme. The pre-Christmas break was booked by Jyoti Scarsbrook, one of the 'tribe', as Suzanne calls their solid group of friends, all of whom have children with Down syndrome.

For the past 18 years, following the birth of their daughter Savanna, the couple have been part of this close-knit group of parents they met through The Champion Centre, which provides early intervention services for infants and young children in Canterbury with significant disabilities.

The mothers bonded over the weekly visits to the centre and since then the families have always been there for each other, offering support and sharing strategies. “It's our tribe; it's the Down syndrome tribe,” Suzanne says.

Jyoti's plan had been to get as many of their group away together as possible to support Suzanne and Chris, but with everyone's pre-Christmas commitments it was just too tough to organise.

Suzanne says she and Chris needed to rest – “not just for me



Friends from the 'Down syndrome tribe' get together to celebrate Christmas and whenever else they can.



Fresh from their break, Suzanne and Chris shop for trees with (from left) Savanna, Jesse and Alani.

but for Chris as well. He has had a lot of stress. The other times we have been away together have been for appointments". However, supporting Suzanne through her illness affected Chris's job and he had to find a new one.

Just as the pair left for the resort there was something to celebrate. Suzanne's doctors reported that there had been no further spread

of the cancer. “We have got to the place where there is nothing new, so it's time to rest and heal.” She says they did that sitting, chatting and looking out at the lake. Then it was home on Sunday to go Christmas-tree shopping with the kids.

The following weekend they joined their friends for their Christmas party, as they always do. The get-



# perfect time to heal



manage it.

together included seven couples. During the year the women meet more often than the men, grabbing the chance to catch up while their children with Down syndrome are attending the Up Club.

“This group has supported me and Chris through this diagnosis; they all are a tremendous support with phone calls, prayers, meals, cleaning, baking, flowers and many words of encouragement. Jyoti came to every chemotherapy session, which helped keep my mind lifted,” Suzanne says.

“It’s just a friendship that has gone on for all these years,” Jyoti says. “It’s just good to know you are not alone.”

Jyoti and husband Paul, along with one other couple from the group, will be taking breaks with the ‘Take a break with us’ programme early this year.

Chris and Suzanne had a lakeside room at Peppers Clearwater Resort near Christchurch.



Jyoti Scarsbrook, pictured with her daughter Georgia, has been encouraging friends in her Down syndrome group to take some time out through the IHC ‘Take a break with us’ programme.



## Take a break gives 144 families a breather

A total of 144 families planned, booked or took a break from the demands of being carers in 2019, thanks to the IHC ‘Take a break with us’ programme.

The programme, which started in mid-2017, is partly funded by the Zena Elsie Orr Memorial Trust and the IHC Foundation, and supported by Millennium & Copthorne Hotels NZ, Waipuna Hotel and Conference Centre and IHC donors.

While some head to favourite holiday spots, many families choose to stay in their home towns because they want to be close to their children or family members if they choose not to take them, or it’s simply easier if they don’t have to travel far.

In selecting hotels, ‘Take a break with us’ organisers try to limit the travelling time to no more than three hours. We use holiday homes for larger families.

Only members of IHC can apply for the break.

### ‘Take a break with us’ breakdown for 2019:

- 144 short breaks – 487 actual room nights used as some families need more than one room
- Most referrals were self-referrals; the remainder came from other providers, organisations or other families
- Accommodation providers – more than 50 providers throughout New Zealand.



Jake Miller (seventh from left) with his Tru-Bilt workmates in the manufacturing workshop.

## Jake's job is changing his life

Jake Miller has landed a job working for a Dunedin manufacturer of industrial doors. He is gaining confidence and making new friends. It is changing his life.

Jake is 21 and has autism, and this is his first proper paid job since he left Taieri College in 2016. He wants to work. He has been lending a hand at his father Michael's kitchen joinery workshop and, even now when he has regular employment, he still works a day a week as a volunteer car groomer.

But being willing to work is not enough. One of the toughest things facing young people with disabilities is finding a job once school is over. In Jake's case it was his employer who came looking.

Mark Taylor, General Manager of Tru-Bilt Industries, decided he wanted to offer an opportunity to a young person with a disability. He had a recruitment agency approach IDEA Services

in Dunedin to find the right person and Jake, who attends IDEA's Switch youth service, was the successful candidate. He is on a one-year contract subsidised by the Ministry of Social Development's Mainstream Employment programme.

Mark says working for Tru-Bilt has been a steep learning curve for Jake, but also for the company in understanding his capabilities and knowing how best to support him. On Mondays and Wednesdays Jake works in the manufacturing workshop where he might be lifting, sweeping or packaging. On Fridays his job is to clean the offices.

Having a willing team around Jake has made all the difference to him being able to complete tasks. One of his chief supporters is IDEA Services Support Worker Jade Bray, who has come up with visual prompts to help Jake know how many bolts need to go into a package, or which cleaning tasks need to be completed.

Danielle McConnell of recruitment agency Human Connections Group says if there's an issue, Jade arrives at Tru-Bilt and can come up with an answer off the top of her head. "She is involved at every level. I am privileged to work with Jade, who can provide initiatives and strategies that I wouldn't have thought of."

Jake says he likes it at Tru-Bilt. "I feel really happy and really great – and it gets me out of the house," he says. "I like the people as well. I like it all."

Shayne Miller, Jake's Mum, says he is more focused. "He has a purpose to get up and get organised in the mornings." He is also walking further – between his Dad's workshop and Tru-Bilt – and gaining in confidence.

Jake's growth in confidence is "one of the things that gives us a real buzz", Mark says. "His Mum says his confidence levels have gone through the roof."

# WORLD-IHC tote bags are hot sellers



Dame Denise L'Estrange-Corbet with artists Christina Van Der Hooft, Joanna Lynskey and Jordan Chow.

WORLD brand tote bags featuring stunning designs by IHC Art Awards artists were hot sellers in the lead-up to Christmas.

WORLD celebrated its 30th birthday with the release of the special limited-edition reusable bags to support the IHC Art Awards. Profits go to the artists and the IHC Art Awards.

The four designs are *Budgie* by Andrew Young, *Zebra* by Jordan Chow, *Untitled Orange Dots* by Christina Van Der Hooft and *Cats* by Joanna Lynskey.

"To date we have sold 700 of the IHC collaboration bags, which we are very pleased with," says WORLD co-founder Dame Denise L'Estrange-Corbet.

"People from all over the country

have been so supportive of the project. A lot were sold as Christmas presents, and a company bought all their customers bags instead of bottles of wine, which was a really nice thing, to support such a worthwhile cause."

Dame Denise couldn't say which designs were more popular.

"We printed the same amount in each, and I felt people were just happy to support the cause, so if the design they chose was not available, they were equally happy to choose another," she says.

"WORLD will be working on this project again for a launch later this year. I feel it is something that has great growth potential for IHC."

Artist Joanna Lynskey, who also works for WORLD, was happy to add some value on launch night by

offering a free signature on all her *Cats* bags.

IHC General Manager Communications Gina Rogers is excited by the success of the tote bag project. She says WORLD and Dame Denise have shown a huge commitment to people with intellectual disabilities, including artists. "The IHC Art Awards have run for 16 years and Dame Denise has been a key part of its growing success," says Gina. "She has been generous with her artistic knowledge and time, both as a public ambassador and behind the scenes with individual artists."

Denise's association with the IHC Art Awards started in 2009 when she became a judge. In 2017 she became the IHC Art Awards Ambassador, travelling the country, meeting artists and encouraging them to enter the awards.

# Advocates see gaps for adults at risk



A merger of two organisations working to protect the interests of adults with intellectual disabilities will provide stronger support for people at risk from abuse, harm and neglect. The merger will also build pressure for a mechanism to safeguard adults between the ages of 18 and 64.

In 2019 the Personal Advocacy Trust (PAT) and the Safeguarding Adults from Abuse (SAFA) collective joined forces to strengthen the advocacy and safeguarding services on offer to adults. The merged organisation is called the Personal Advocacy and Safeguarding Adults Trust (PASAT). Since January 2019, PASAT has had enquiries or referrals from 50 adults at risk. Its role is well articulated by its new Māori name,

Te Kahu Haumarū – the Cloak of Safety – gifted by the mana whenua of Wellington Te Āti Awa Taranaki whānui.

Erika Butters, PASAT National Advocacy Director, manages the advocacy side of the organisation, which now includes short-term advocacy and supported decision-making among the services it offers.

Sue Hobbs, Safeguarding Adults National Director, manages the safeguarding response, which now extends beyond Auckland, and has widened to include services alongside advice.

Erika says adults at risk are often invisible, but the new organisation will be able to gather evidence of support needs to take to Government. “The partnership has broadened the scope to do more, to help more. The trustees are not looking for business opportunities,

they are recognising the need and responding to need,” she says.

PAT was established in 1967 by families supported by IHC who wanted to ensure the wellbeing of their disabled family members once parents had died. The organisation has recently been restructured from having a largely volunteer workforce to one employing professional advocates and ensuring quality and consistency of services. PASAT employs 13 advocates.

Lifetime membership and advocacy is funded by the payment of fees. Short-term advocacy is paid for by the person who has requested it or, if a disabled person or family cannot afford to pay, through philanthropic funding. Supported decision-making, at present offered in the MidCentral District

*Continued on page 13*



(From left) The Independence Collective's Nathan Martin, Cameron Stichbury, Neville Pugh and Janie Tutton are ready to market their new range.

## The Change Maker is coming

At Beervana 2019, a group of young Kāpiti entrepreneurs unveiled their new brand of craft beer, Change Maker. Now it's become a commercial reality.

The Independence Collective has commissioned four independent brewers to make 40,000 litres of the new Change Maker range – pale ale, pilsner, IPA and XPA – and it's scheduled to hit supermarket shelves throughout the country this month.

Each brewery will make 5000 litres (or 10,000 bottles) of beer.

Duncan's Brewing Company in Kāpiti will produce the pale ale and Moa Brewing Company in Blenheim will make the pilsner, while Auckland's Behemoth Brewing Company will produce the IPA and Sawmill Brewery the XPA.

Nathan Martin, Janie Tutton, Cameron Stichbury and Neville Pugh are members of The Independence Collective, which is managed by IHC's Gordon Cumming. Gordon is finalising a distribution agreement with Foodstuffs to get the bottles on the shelves of New World and Liquorland outlets.

The collective members say its name says it all. "We are the change we want to see in the world for both ourselves and for other people with intellectual disabilities."

"We have got an amazing story to tell," Gordon says. He says the beer is being made by award-winning brewers and he is confident it will go down a treat.

Change Maker began life as Neville, a craft pale ale, brewed in partnership with brewer George Duncan. The group has been selling their beer since October 2018 to Kāpiti bars and cafés, as well as online and at selected events.

*Continued from page 12*

Health Board region through the Mana Whaikaha disability support system prototype, is funded by the Ministry of Health.

SAFA started in 2010 and came out of the self-advocacy organisation People First New Zealand, and later broadened its scope to include any adult at risk. Sue Hobbs says its merging with PAT has allowed the collective to move from solely offering advice to being more responsive. "We are now able to provide a service to people."

Its integrated response to safeguarding adults at risk was honed in Auckland in 2016, working with Waitematā Police and the Waitematā District Health Board. During a six-month pilot project 40 adults were removed from unsafe situations and connected with support and services.

Aside from continuing its work in Auckland, PASAT is working in partnership with Safeguarding Vulnerable Adults Taranaki to deliver a SAFA service in Taranaki.

There is also a safeguarding response in MidCentral as part of Mana Whaikaha. Sue says in 2020 PASAT will continue to work with adults at risk in situations that may include anything from financial abuse to family violence. "We are not a crisis response organisation. We are there to work with police and other agencies as appropriate," Sue says.

Funding from the IHC Foundation supported the redevelopment of PAT and the subsequent merger of the organisation with SAFA.

# Researchers urge people to get their eyes checked

Researchers from the Department of Ophthalmology at the University of Auckland are putting out a final call for people to get their eyes checked – which may save their vision.

By early March 2020, the project team hopes to have signed up 200 people in a study to find out how common keratoconus is in New Zealand. The disease causes progressive vision loss due to the thinning and bulging of the cornea, which is the clear protective covering of the eye.

In 2017 the team tested 98 athletes with Down syndrome at the Special Olympics National Summer Games in Wellington. They found that as many as one in three had keratoconus.

The results inspired the Keratoconus in Down syndrome (KIND 21) project – the first research of its kind in New Zealand. So far, the KIND 21 team has provided comprehensive checks for 100 people.

Optometrist Joyce Mathan, who is working on the project for her PhD, says the team wants to draw attention to this screening, now that corneal collagen cross-linking treatment is available. She says the aim of the study is to provide evidence about keratoconus in people with Down syndrome and then to raise awareness among individuals, families and support people of the need for regular checks.

Heather Reynolds, a registered nurse and member of the KIND 21 team, says the treatment that is available now is miraculous.



Joyce Mathan (right) and Heather Reynolds with a KIND 21 study participant.

She says that in the past people could lose their vision and the only treatment on offer was a corneal graft, using donated corneas. “A corneal graft is end-stage treatment,” Joyce says. “This can be avoided by timely corneal collagen cross-linking.”

The optimal age for screening is between 10 years and the early to mid-teenage years. The study is open to anyone with Down syndrome 10 years or older, living in New Zealand and able to express agreement to participate. An assessment to detect keratoconus is provided as well as a general vision and eye health assessment. Participants and support people will be told if keratoconus is detected.

Follow-up visits may be needed to monitor the cornea for changes if keratoconus is present.

If change does occur, a referral for corneal collagen cross-linking will be provided. This is the standard treatment used to slow down or stop keratoconus from progressing. The treatment is fully funded through the public health system.

Because this study is part of a PhD project there is no charge for the appointments. The assessments are held at the University of Auckland, but if there is a need for follow-up treatment, this can be done locally. The project team also includes Dr Samantha Simkin, Dr Akilesh Gokul, Professor Dipika Patel and Professor Charles McGhee – all from the Department of Ophthalmology, University of Auckland.

**To find out how you can take part, please contact Joyce Mathan at [joyce.mathan@auckland.ac.nz](mailto:joyce.mathan@auckland.ac.nz)**



Ryan Mollgaard, pictured with Sara Hillier-Jones, was confident to drive through the Tauranga city centre on his first driving lesson.

## Hard work pays off as Ryan gets behind the wheel

Ryan Mollgaard has mastered the theory – now he is behind the wheel of a car and practising to take his driving test.

Ryan, 24, wants to work as a gardener, but for that he needs his own transport. A year ago, the Tauranga man started studying for his learner licence, working with IHC volunteer Sara Hillier-Jones.

“I got my provisional licence on 17 December. It is my goal to learn how to drive a car,” Ryan says. “It has been pretty tiring. The hardest was the give-way rules.”

Ryan went online to learn the Road Code, doing the practice tests repeatedly. Ryan doesn’t find handling a machine hard – he learned to fly an aircraft in Morrinsville as an air cadet – but it’s the theory that trips him up. Ryan has autism linked with ADHD (attention deficit hyperactivity disorder).

Sara and Ryan started the project in February last year and met at the Greerton Library in Tauranga as often as twice a week, using the public computers to go online to drive.govt.nz. “There are quizzes you can do at the end of each segment. We worked through all those and, once we had completed them, we went over them again,” Sara says.

A perfect score is 35, and she knew Ryan was ready to attempt the test when he was scoring in the 30s. On his first attempt in October he missed four questions – you are allowed only three misses. But in December he passed with all 35 questions correct.

“He was over the moon. It was wonderful. It was worth every minute,” she says. “His perseverance has just been amazing.”

Sara, who focuses on skills-based learning as part of the IHC Volunteer Programme, went along to Ryan's first driving lesson in January to lend some support. “The instructor, Dave, drove to a quiet area before he let Ryan take the wheel. He was so impressed with Ryan’s driving that instead of swapping and driving back into the city centre, Dave had Ryan drive back. At the end of the lesson he told Ryan that it was very rare that someone would drive in the city centre on their first lesson.”

Ryan has lived with Ron and Shirley Sitters since his mother died when he was 14. “He calls us his grandparents,” Ron says. “Shirley and I are very, very proud of the way Ryan has come through. Sara has been absolutely outstanding.”

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