

# Community MOVES



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March 2019

**ihc**  
IN YOUR COMMUNITY



# Personally speaking

At the start of each year we hold the IHC Annual Appeal to ask members of the public for financial help to allow us to keep supporting people with intellectual disabilities.

This year's appeal coincides with our 70th birthday. A huge amount has been achieved on behalf of people with intellectual disabilities over that time, particularly in enabling people to move out of institutions and into the community. But it is disappointing that so long after families first started their campaign for change in 1949, people with intellectual disabilities and their families still struggle to get a fair deal in many other respects.



We believe everyone should have the opportunity to achieve their goals and live good lives in their communities and that everyone has the right to make as many choices as possible in their own lives.

There are many people who need 24/7 support. We are ensuring our core residential and vocational services are the best they can be and that they will be here for another 70 years and beyond.

Government funding is not enough to ensure everyone in New Zealand has a good life. Our charitable and community programmes are as essential today as they were 70 years ago. Many of the challenges are new – many are the same as they have always been.

Some people need a lot of support and some need only a little – either way IHC is here for them and for their families – but we can't do it alone.

Donations to IHC make an enormous difference to people right throughout the country. The money raised through the Annual Appeal is spent on IHC services that are not funded by the Government, including:

- A new Family-Whānau Liaison team to connect families with the support they need
- Advocacy on behalf of individuals or wider groups struggling to get a fair deal
- IHC's library – the largest intellectual disability library in the country providing free information to anyone in New Zealand
- A volunteering programme that encourages long-term one-to-one friendships and provides short-term programmes where a person with an intellectual disability can learn a specific skill
- The Take a break with us programme that is providing a new kind of respite and is helping boost our membership.

If you give to IHC as part of the Annual Appeal, or through any of our fundraising programmes, please accept my personal thank you.

Ralph Jones  
IHC Group Chief Executive

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# Dane grabs his America's Cup moment



Sailability Wellington volunteer Darrell Smith (left) and Dane Muir were two of many being photographed with the America's Cup at the opening of the new Titahi Bay Boating Club jetty.

For Dane Muir, possibly the best thing about sailing is being in a boat with his friend Darrell Smith – or better still, getting his photograph taken with Darrell and the America's Cup.

Dane was in the official party, along with Sports Minister Grant Robertson, when the Sailability Wellington Trust recently opened its new all-tide jetty on Porirua Harbour. The America's Cup made a special guest appearance at the Titahi Bay Boating Club, loaned for the event by the Royal Yacht Squadron in Auckland.

Dane, who is an IDEA Services Service User in Porirua, sails most Thursdays with Sailability Wellington. The organisation offers people with disabilities the opportunity to sail. Sailability Wellington Trust Chief Executive Don Manning says if Darrell isn't free to sail when Dane arrives, he waits until he is.

And, while Dane is learning how to handle the boat, he is also building lasting friendships. Dane and

Darrell, a double amputee, enjoy a regular joke when they meet. Every week Dane will ask Darrell where his legs are.

"I might just say they are in the car, or they are having a rest at home," Darrell says. Darrell has been sailing since he was a boy, but has become progressively disabled with a condition that eventually meant the removal of both legs.

Darrell says Dane does know the real story, but the leg jokes help to break the ice each week. "That does give us a bit of a connection."

Darrell has been volunteering with Sailability Wellington for eight years. Dane has been sailing for six years and he is on deck every week if the weather is good and the tide is right. "He is a lovely guy; he knows us all," Darrell says. "Every time he gets in the boat he asks about my boy and my daughter and my grandson."

Don Manning says almost 190 people sail with Sailability

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**COVER IMAGE:**

Sailability Wellington volunteer Darrell Smith and Dane Muir take a moment with the America's Cup at the opening of the new all-tide jetty at the Titahi Bay Boating Club. See story this page.

# Where there's a will, there's a job

The Hibiscus Coast Community House at Orewa was Becca Gibbs' happy place, until a fellow volunteer wasn't happy about her being there and Becca lost her job.

The place where she had been welcomed and hugged each week had closed ranks, says her mother, Bridgit Gibbs.

Becca, 26, had volunteered at the op shop on Thursdays for about a year. "The manager knew that Becca needed to be told what to do."

Becca had recently started going in on a Monday as well, but a fellow volunteer objected to working with her. "She said that she couldn't cope with this girl and her disability and she shouldn't be working there."

Bridgit says Becca was offered the opportunity to move to another day, but that was the day Becca attended the IDEA Services Kingswood Vocational Centre and in any case she no longer felt the op shop was a place where Becca should be working.

Becca has not had paid work since she left school at age 21. She attended the Adults in Motion life skills programme and has volunteered at a local café and a special school, but attempts to find work are often blocked. "You know what they throw in our faces – health and safety," Bridgit says.

She says young people with intellectual disabilities might be well supported while they are at pre-school and school. "That is all lovely. But what do they do with the rest of their lives?"

Becca has an intellectual disability, with dyspraxia and developmental delay, and her



Becca Gibbs now has a new job, volunteering at the Orewa Red Cross Shop.

speech is difficult to understand. And she loved her days at the op shop.

"She's cheerful. She's happy. She enjoys being around people. She can follow instructions as long as there are not a whole lot of them in one go. She loves helping. She is very good at sorting things if someone shows her what to do," Bridgit says.

News of Becca's plight galvanised the community and brought several offers of help. One offer from the Orewa Red Cross Shop was just right, and even closer to home than her old job. Becca started as a volunteer in early February.

IHC Director of Advocacy Trish Grant says the incident at the Hibiscus Coast Community House violated Becca's right to be included in her community. It was also a missed opportunity for the shop's management to learn and develop more inclusive attitudes. People with intellectual disabilities could turn out to be "fantastic employees" with the right support.

Since then the Hibiscus Coast Community House has been in touch with Trish to discuss how they could better support people with intellectual disabilities. Trish says it was a positive discussion and all credit to them for wanting to improve their practices.





Bart Uy explores 'Bart's World' at Auckland University of Technology, guided by game creator Isaac Pattison.

## Bart can choose the best of both worlds

From the starting area of new virtual reality game 'Bart's World' you have a choice of two doors. If you teleport through one door you find yourself on a high, grassy hill, where a path leads down to a waterfall and trees. Enter through the other door and you are in a games arcade with gaming machines and prizes.

Bart's World was created for Bart Uy by his friend Isaac Pattison. It was Isaac's final-year project for his Bachelor of Design degree at Auckland University of Technology (AUT) last year. And, as the name of the game suggests, it is based on how Bart likes to spend his time. Bart finished at Unitec last year with certificates in employment skills and community skills, and is volunteering at a Mt Roskill supermarket while he looks for a job.

Bart and Isaac have known each other for less than a year and share a love of gaming.

Bart was looking for a friend through the IHC's volunteer friendship programme and Isaac was looking to volunteer. They live at opposite ends of Auckland, but this doesn't stop them hanging out together.

At first Isaac hesitated about signing on as a volunteer because he thought he wouldn't be able to spend enough time with Bart during the final year of his degree. But Bart has provided the inspiration for his course-work project. "I was making a fun playground area for Bart to enjoy the things that he likes. It ended up becoming more about giving him a cool games space," Isaac says. "Everything except the water is hand made. I programmed it and designed it all. I took a long time planning it all."

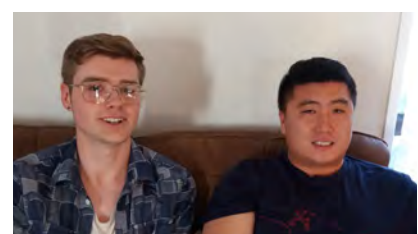
Isaac says the game has two main aspects. The nature area is for exploration and the games area is about interacting.

In Bart's World, Bart can play ten-pin bowling, basketball and Skee-Ball in the games arcade or pick

up stones and throw them into a pond in the nature zone. Isaac also included a tree in the game, which exists for real in Albert Park in central Auckland, where they often sit and talk.

Isaac showcased the game at AUT at the end of the year and invited Bart and his parents to come and experience it. "He liked it a lot," Isaac says. "He didn't want to stop."

Bart was quick to see the advantages of the virtual reality bowling. He said it was better than the real thing as he could have as many turns as he liked at bowling without paying. Isaac has now purchased his own VR goggles and hand controls, so he can take the game to play at Bart's house.



Bart and Isaac have become friends through IHC's volunteer friendship programme.

# Year of music therapy provides data for study

A team of evaluators, including ASD experts, is assessing the impact of a year's worth of music therapy for Kiwi children diagnosed with autism.

The Victoria University of Wellington project is being led by Dr Daphne Rickson from the New Zealand School of Music: Te Kōkī. Her goal is to provide evidence about the benefits of music therapy so that more children can take advantage of it.

From January to December 2018, music therapists in Wellington, Christchurch and Auckland provided weekly music therapy sessions for 10 school-aged children at school, at home or in studios. The therapists, who were asked to follow their usual music therapy practice and to work directly with the families, have now completed case studies on each child, and these are being evaluated in the second stage of the project.

Daphne, Senior Lecturer in Music Therapy at Victoria University, designed her study using a narrative assessment method that she hopes will convince policy makers and others that music therapy is worth funding. The IHC Foundation is investing \$100,000 in the two-year project.

Daphne says this method of assessment is used already in many schools to report to parents and others in the community about the way children are performing.

She says there is a need for evidence in New Zealand and overseas on how music therapy can influence a child's development of communication skills, including attention,



Daphne Rickson, pictured with Ronnie, 3, has a team of evaluators looking at reports from music therapists.

imitation, initiation, turn-taking and emotional expression. But it has been hard to convince funders because music therapists use an improvisational style that responds to the child in the moment. Each situation is unique, so controlled trials are difficult.

The progress of each child participating in Daphne's study will be assessed by 10 evaluators, five who know the child and five experts in ASD who don't. The evaluators who know the child will generally include a parent or family member and may also include a teacher, speech and language therapist, or psychologist. Daphne says grandparents feature highly in this group because of the prevalence of shared care, but it had proved difficult to recruit the children's teachers and teacher

aides because of their heavy workloads.

All the evaluators will be answering the same questions and, from the 100 total evaluations, statistical data will be provided for the effectiveness of music therapy generally. The evaluators will also write a short summary of the case, which will help with understanding how and why some approaches will work for some children and not others. The university's Information Technology Services department has created a purpose-built online platform for collecting and engaging with the data.

From April, Daphne will start analysing the data, which includes written reports and videos, to determine the impact of the therapy.



# Stratford Aero Club salutes 'missing man'

Mourners first heard the rumble of aircraft in the distance and then saw five aircraft flying in formation to pay tribute to Stratford man Greg Tolland.

Greg's burial was put on hold while family and friends watched the flypast by the Stratford Aero Club's Sport Flyers. The pilots flew in a 'missing man formation' and tipped their wings as a mark of respect. The aerial salute is performed typically in memory of a fallen pilot, where one of the planes pulls up and flies away, leaving an empty space in the formation. The last plane released a stream of smoke.

Greg was a newcomer to the club but planes were his passion, and the club made him an honorary member and presented him with a club cap and T-shirt.

Greg's support worker Roni Lamont had the bright idea of taking him to the Stratford

Aerodrome six months ago and it became a regular Sunday outing. "Towards the end the only place he wanted to go was the aerodrome," Roni says. "Greg knew everything there was to know about aeroplanes."

Nick Furmage, President of the Stratford Aero Club Sport Flyers, says Greg had always been interested in aviation and would have liked to have been a pilot, but his disability prevented that.

Greg's mother June Tolland joined them on a couple of visits. "Sometimes there was a lot of flying and sometimes there wasn't," June says. Greg had his 56th birthday just days before he died on 23 December.

Roni says Greg's last visit to the aerodrome, planned for early December, had to be abandoned because he wasn't well enough.

IHC has supported Greg since 1994 and also his sister Christine and brother Kenneth. All three siblings were born with congenital spastic tetraplegia, a rare genetic condition

that causes muscle weakness and tightness in the limbs.

Greg, Kenneth and Christine lived in a purpose-built IDEA Services house in Stratford, with Greg later moving to a smaller flat that he shared with a flatmate. Christine and Kenneth both died some years ago and Greg had become increasingly frail and relied on a wheelchair to get around.

Roni phoned Nick once mourners were on their way to the cemetery and soon heard the planes. "We caught sight of them and everybody was covered in goose bumps," Roni says. But no-one was expecting five planes. "Nick thought he was going to be doing it on his own." But club members had called him wanting to be part of the tribute.

June says Greg's enthusiasm for aircraft came from his father Jim, who served in the Royal New Zealand Air Force in communications. Greg loved motorbikes and fishing, as well as planes. "He was very determined. He always said he was going to walk again; he never let that go."



Greg Tolland enjoyed regular visits to the Stratford Aerodrome. (Inset) Greg was presented with the club cap and T-shirt.





Mike Scaife of RM Software (left) and Te Rito Gardens Coordinator Steve Wilson in front of the solar panels that have been installed at the existing site.

# Te Rito Gardens plans its new home

A community garden that supports people unable to get paid employment is starting again – from the ground up.

Te Rito Gardens has been operating for nearly 10 years from the grounds of the old Porirua Hospital and has so far supported more than 240 people – many with intellectual disabilities – to gain practical and life skills. But Te Rito is on notice to move to make way for a housing development. It has been offered a new location with a long-term lease, but this is a bare site and the volunteers must now build the infrastructure needed to get their organics cooperative up and running again.

Te Rito Gardens Coordinator Steve Wilson and his team of 24 volunteers plan to work out of two

converted shipping containers until a permanent building can be erected, and to set up a large covered area that will be used for plant propagation and workshop facilities. The gardens will be powered off-grid by a solar-powered system.

In 2017, the IHC Foundation contributed \$20,000 towards the installation of the solar panels and battery bank to run the propagation house and irrigation pumps. In December 2018 it made a further grant of \$16,800 towards constructing fencing and windbreaks and a 50,000-litre water storage tank.

As hard as it is to uproot themselves and their plants, the Te Rito volunteers see many opportunities at their new flat and sunny site bordering Mitchell Stream in Raiha Street, Kenepuru, where they have

a chance to build an even more sustainable enterprise. They are hoping that earthworks on the site will be completed this month and they will be in their new location by September 2019.

The mains power at the Porirua Hospital site has already been disconnected so Mike Scaife of RM Software volunteered to install the off-grid power system at the current site so that they can continue to provide services until the shift. This is a small, temporary solution to provide immediate low-storage AC power to the existing site.

Stage two will involve fitting the remaining batteries, along with associated electronics and control systems.

The solar-powered system, being paid for by the IHC Foundation, will power the irrigation pumps, control





## ext move

systems, lighting, fridge for seed storage, and a small office with tea-making facilities. These will be run from a 24/48-volt bank of lead carbon battery cells and charged by solar panels mounted above the propagation structures. A small petrol-powered generator will be on hand for extended periods of insufficient sunshine.

Te Rito's main business is to supply local eco-sourced native plants, particularly for planting along riverbanks and in wetlands. It grows many thousands of plants from seed or by propagation. It sells these to local councils and environmental groups. It is also involved with the EnviroSchools programme, supplying plants to 10 local schools.

Until recently Te Rito has been growing organic vegetables for sale, and this part of the operation will be resumed after the shift.

## Jacob has a job among friends

Jacob Keswell has a job he loves, and works among people who have become his friends and mentors.

At Te Rito Gardens Jacob, 23, gives everything a go and is succeeding as part of a supportive team.

"There is always something different to do every day – lawns, weeding, composting, potting up," he says.

Jacob has dyspraxia, which affects his coordination and concentration. "I can get confused quite easily. My brain will tell me to do one thing and my hands will tell me to do another."

He left Mana College in 2014 without enough credits for NCEA, but with an introduction to horticulture at Te Rito thanks to the college's Gateway Programme. He has been volunteering there ever since he left school. "Every year a new challenge comes along," he says.

"My confidence has gone up. I am not as nervous. At school I didn't really talk to anyone. Up there you get to talk to people, to know

people, to feel more confident in yourself. I have somewhere to go. I know what I am going to be doing, the people who are going to be there."

Te Rito Gardens is a social enterprise cooperative that shares the proceeds of sales monthly based on the hours worked by the stakeholders. "We are volunteers, but we get a small payment," Jacob says. Jacob is one of the stakeholders and works four days a week. In winter they work from 9am until 3pm. Summer hours are shorter from 9am until 12.30pm.

Jacob's mother, Michelle Williams, says he enjoys getting his hands in the dirt. "I just want him to be happy and to be doing something productive. He is picking up skills. He is learning. It has made him more confident."

The volunteers also connect with the wider community through planting schemes and clearing people's properties.



Jacob Keswell and the Te Rito team recently helped Porirua City Council and some local volunteers to plant along the railway lines at Plimmerton.

# Calling an 0800 number is not the answer

The new IHC Family-Whānau Liaison team is helping isolated and stressed families to find the services in their communities that can help them.

So far the liaison team numbers three – Jim Callaghan in Northland, Suzanne Downes in Manawātū/Horowhenua and Sheridan Myall in Christchurch. They will soon be joined by a fourth member in North Otago.

Their job is to be the ‘go-to’ people for families who need advice about what services and agencies can do to support them. They are a friendly face on the often faceless bureaucracy.

Janine Stewart, IHC General Manager of Programmes, says for a long time families have struggled to get information and access to services in their communities, and to understand what help they are entitled to. For many families the task of caring for a disabled child or family member is overwhelming and there is little energy left for the red tape.

“You need a face – someone who is part of their community and who understands their community. Calling an 0800 number in Wellington doesn’t work,” Janine says. “Communities throughout New Zealand are struggling to support people with disabilities and mental health issues. And when people are in crisis they need a person – we want to help.”

Janine acknowledges that the team is small and will be thinly stretched. But their role is critical. “There is a lot of carer burn-out out there,” she says.

IHC National Manager Volunteering Sue Kobar, who manages the team, says the referrals are coming in thick and fast from schools, other disability providers and community organisations. And some of the problem areas

are obvious. “Families are being referred to an agency only to find out they are on a two-year waiting list. If we know this in advance we can avoid referring people to agencies with waiting lists,” she says.

“We have found that people who are entitled to benefits are not getting them. Some families don’t know what they are entitled to and others need support to apply. There are all sorts of barriers and often a strong sense of frustration by the time we are contacted. Our goal is to help them to get access to the services they need.”

The liaison staff are being funded as part of a two-year pilot study by the IHC Foundation. How they work will be shaped by the needs of the families in the areas they serve. Already the regional differences are emerging.

## Jim Callaghan

Jim Callaghan is based in Whangārei and he doesn’t have to look far to find families who are struggling on their own to care for children with intellectual disabilities, and who are also struggling financially.

“I haven’t met anyone with a family member with an intellectual disability who is not struggling in some way.”

There are organisations that can help, but services are fragmented and families often don’t know about them. “There is not a lot of coordination of stuff and a lot of isolation,” Jim says.

During the school years things are often easier for families. “In a lot of rural communities people with a disability are known and they are connected anyway. It’s what

happens after that.

Everyone else goes,” he says. “When these kids leave school there is nothing out there.”

Jim says there is not much trust in government agencies and health services. “A lot of families that I have are nervous about approaching organisations like WINZ. Going to WINZ is not the easiest thing to do; you have to make an appointment online.”

He says people find it too hard. “They live rurally, so actually just travelling can be a problem. If you get an unfriendly place like a WINZ (Work and Income) office at the other end – that can be a problem for you.”

But, Jim says, Work and Income has health and disability advisors who are very helpful and he is working with them to ease the path for families.

Above all, the Family-Whānau Liaison team is there to listen to families “because nobody else seems to want to”, Jim says.

“What we do is tease out the things that are available to them that they may or may not know about – things like the disability allowance, or clubs that are open to them. I do see the role as a privilege. I am invited into these families’ homes and I am invited into their lives to share things with them that are quite personal. People don’t have to jump over hoops to see us.

“One of the most important parts of this role is relationships – the community relationships. You can’t do without them. Lots of people in the sector are very kind. They are happy to share what they know.”





The new IHC Family-Whānau Liaison team – Suzanne Downes (Manawatū-Horowhenua), Jim Callaghan (Northland) and Sheridan Myall (Christchurch).

### **Suzanne Downes**

Suzanne Downes knows a lot about what families in Manawatū and Horowhenua need. Before she took on the liaison role, she spent two years doing research for IHC asking local families about the kinds of pressure they were facing and what would ease the pressure points.

She has also worked on the Enabling Good Lives (EGL) provider group. Manawatū is the first region to trial the new EGL disability support system. She is also working with researchers on a new project, funded by the IHC Foundation, that is collaborating with families, councils and iwi to co-design solutions to meet their local needs.

“My focus is very much now on community development, not so much working with individual cases.”

Suzanne is now based in Levin at a new community hub where she can easily connect families with a whole range of community service providers. She says lack of respite for families in Manawatū and Horowhenua is a huge issue with

little in the way of after-school care or holiday programmes. “Social isolation is a big one. Some of these families have no-one.”

The difference between Suzanne’s team and the Ministry of Health ‘connectors’, who are employed under the EGL trial, is that the IHC team is not funded to take on cases. It is the initial point of contact for families and will find them the best people to help.

### **Sheridan Myall**

In Christchurch, Sheridan Myall has been spending a lot of time with families and schools talking about the experiences of young people with disabilities and meeting their Special Education Needs Coordinators. She covers 145 schools across the city and most of her referrals have come from schools on behalf of families.

Sheridan says some of the families she encounters have limited means and are not able to access basic services. Others have means but need support to access more than basic services. She says she is learning what’s available for these families and developing relationships with providers.

She says issues like foetal alcohol syndrome are becoming more apparent, along with undiagnosed intellectual disabilities. “People, for a variety of reasons, require services but haven’t got a diagnosis of intellectual disability.”

Without a diagnosis, these families will not receive funding for support services. Others receive carer support hours but struggle to know how to use these effectively or to find respite services. Sheridan says she has introduced families looking for after-school activities to Special Olympics and to Riding for the Disabled.

“One of the things that has become apparent to me is that there are some very sad stories out there of people with limited resources.” Sheridan says people in a low socio-economic bracket are finding it harder and struggle to look outside the square.

### **Oamaru – North Otago**

The team will soon be joined by a new member in Oamaru. This position is to be fully funded by the North Otago IHC Association.

# Roll out the mats – it's the last Sunday in July



Among friends in downtown Dannevirke are (from left) Miriam Telford, Support Worker Noella Hewitt, Catherine Pratt, Phillip Poulton, Support Worker Linda Owen, Chelsea Victor-Gordon, Garry Small and 'Fire Officer' Jo Brown.

In Dannevirke, the last Sunday in July is set aside for the Dannevirke Combined Indoor Bowling Clubs' annual fundraiser for IHC. It's been a circle on the calendar for nearly 50 years.

Since 1971, when the tournament started, \$61,938 has been raised. Over time the number of indoor bowling clubs in Dannevirke has dwindled from six to the two remaining clubs – Sports Centre and Rua Roa – but the support in the town for local people with intellectual disabilities has not faded.

John Johnson, past President of the club, has been organising the tournament for 17 years and he says the town regularly raises more than \$2000 each time. And on the occasions when it hasn't quite reached the \$2000 mark, the club has chipped in the extra. Each player gets a prize and all the prizes are sponsored by Dannevirke businesses.

"You have got to be very, very proud of the Dannevirke community," John says. "A lot goes into it," he says. "A lot goes on behind the scenes."

The money raised comes from cash sponsorship, the sales of raffle tickets, and entry fees from the players who come from across the lower North Island, from Napier, Marton, Feilding, Palmerston North, Pahiatua and Wairarapa. They play for the afternoon in teams of four and there are four games of 40 minutes each. People with intellectual disabilities are encouraged to join a team. John says the teams aren't looking to win, but simply to enjoy the day.

Each year three raffles are held – meat, groceries and vegetables. The only costs deducted from the tally are for two \$20 gift vouchers for the women organising the raffles.

There are three residential homes in Dannevirke – and service users compete each year. All the houses and residents have benefited from the tournament, with new

lounge suites, iPads, garden improvements and a lawn mower. The vocational base in High Street had a shade sail installed last year and the latest tournament will pay for concrete paving underneath.

Majorie Bloor, who has been on the Dannevirke IHC committee for the past 52 years, says her daughter Jennifer was a keen bowler, but has recently been struggling with osteoarthritis. "When it started off it used to be a day tournament and we used to provide lunch. We would cook sausages and mince. It was a happy occasion."

Committee Chair Jose Small says these days the committee members help IDEA Services staff with an afternoon tea. Jose says there is huge support for people with intellectual disabilities in Dannevirke. "We are a very small and tight community."

John is now looking ahead to the 50th anniversary tournament in 2021. "I would like to see it reach 50 years. I would like to see 20 mats in the hall and get 40 teams. I hope to make it a special one."



# Keen bowler retires after long innings

It was his leg that was the problem. Christchurch veteran indoor bowler Allan Gardiner gave up his favourite sport when he realised he couldn't rely on his right leg any longer.

Allan, 86, has been bowling with a Special Olympics team for years and has medals and ribbons from many successful tournaments. He retired only reluctantly late last year as New Zealand's oldest Special Olympics athlete.

"We played against the other people then I decided to give it up because if I get off the walker, then I will fall over on my right leg," Allan says.

Allan has been married to Karen for 18 years and they shared a love of bowling, but Karen has recently retired too.

Allan now has more time for some of his other favourite pursuits – singing, playing the bongo drums and model trains.

Service Manager Amber Tuhua says Allan is a very good singer.



Allan wears his Special Olympics bowling jacket one more time.



Allan Gardiner has reluctantly retired as New Zealand's oldest Special Olympics athlete.

"If he meets someone new, he will sing them a song, and he has a very lovely voice as well."

Allan enjoys singing the old-time songs – and he has four particular favourites: *Show Me the Way to go Home*, *Pearly Shells*, *I Don't Know Why I Love You* and *Rainbow on the River*.

Senior Support Worker Leslie Clarke says he enjoys fortnightly sessions with a music therapist.

Then there's his model train set that has pride of place in the lounge of the IDEA Services Burwood home he shares with Karen and four house mates. A large table supports the track for two trains.

Allan was born in Christchurch as one of six children.

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Wellington in various locations around the Wellington coast, supported by 70 volunteers, and there are 90 on the waiting list.

The IHC Foundation has supported Sailability Wellington since 2015. The Foundation's most recent grant, in October last year, was \$15,000 towards the expansion of the sailing programme and to increase participation of sailors from Porirua, Kāpiti and Horowhenua.

The Titahi Bay Boating Club's existing jetty was strengthened to support the new jetty, which now extends into the harbour by five metres, linked by a walkway and ramp. This gives Sailability Wellington a further 50 square metres of rigging space to set up masts and sails, and new floating pontoons will provide all-tide sailing.

Sailability Wellington will operate and maintain the floating pontoons, but has gifted the new jetty to the people of Porirua, under the guardianship of the Titahi Bay Boating Club. The jetty is named the Duncan Renouf Jetty in memory of Dane's friend, who was another keen sailor. Dane helped to unveil the jetty in his honour. Duncan, who had Down syndrome, sailed solo for the first time shortly before he died in January 2017. Dane points to a photograph of Duncan in pride of place at the Porirua vocational base Te Wa Huri Huri (the Turning Point), where the two men spent a lot of time together.

Lynne Renouf, Duncan's mother and IHC New Zealand Life Member, says he loved sailing and wouldn't miss Thursdays for anything. "He was absolutely enthusiastic. He was very keen to go out on his own," she says. "He was a leader of the pack – out of the van and organising the vests – in his element really. He turned out to have pretty good skills."

# Take a break gives 400 families a breather



Anakin Kingi and his Dad Thomas and Mum Chante had a summer break in Hawkes Bay last year.

More than 400 families have been able to take a break from the demands of being carers, 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 supported by Millennium & Copthorne Hotels New Zealand, the IHC Foundation and IHC donors.

Millennium has sponsored the programme since September 2017 and provides accommodation throughout New Zealand. Twenty-one hotels now support the programme, with Millennium agreeing to provide more than 50 room nights for 2019.

Emily Fraser, Millennium Digital Marketing Coordinator, says

Auckland and Rotorua are popular destinations and many hotels like to roll out the red carpet and make Take a break guests feel welcome.

Millennium Managing Director BK Chiu says: "We appreciate the opportunity to help support these families with the small gesture of these mini-breaks, recognising their selflessness and quiet dedication to their families."

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 two or three hours. We use holiday homes for larger families.

At the start we also offered gift cards and pamper packages,

but the programme has been refined and we now only offer breaks. From 1 October last year, it was decided that only members of IHC could apply for the break. Since the new member rule came in, more than 40 families have registered.

## **'Take a break with us' since 2017:**

- 117 gift packages (\$250 Prezzy cards)\*
- 125 pamper packages (hair or beauty vouchers)\*
- 401 short breaks (487 actual room nights used – some families need more than one room)
- One-third of referrals came from other providers, organisations or other families – the rest were self-referrals.

(\*No longer available)



# Chalyce puts out a call to families



Manawatū Association Secretary Chalyce Attwell is working to make life better for her sister Tarryn.

The Manawatū IHC Association has been relaunched by a group of families determined to tackle some of the most difficult issues facing people with intellectual disabilities in the region.

The Association, which re-emerged in October after a nine-year recess, held a 'meet and greet' in February to hear from families about what help they needed and to boost membership.

One of the Association's first projects is to get better sleepover arrangements at Palmerston North Hospital for parents who want to stay overnight with their disabled children. This is an issue close to Association Secretary Chalyce Attwell's heart. Her sister Tarryn recently spent three weeks in the hospital and there was nowhere for their Mum to sleep. She could borrow a la-z-boy chair from a patient day room, but that could only be used from 11pm and had to be returned by 6am. She opted instead to take in her own camp stretcher. Tarryn, 18, has Down syndrome and she mainly communicates through sign language, using her Mum as interpreter.

The Association is now in talks with the hospital to see whether stretchers can

be provided for other parents. The plan is that they would provide five stretchers and seek sponsorship for a further five, which would be stored at the hospital. "They fold up nice and small. That is why we thought stretchers not la-z-boys," Chalyce says.

The group is also keen to tackle the issue of employment for local people with disabilities by investigating how to fund and set up a business or social enterprise. "We are open to suggestions and ideas. We have got nothing set in concrete, but we know from what we have heard in the community that employment is a big priority."

So far it's a small committee of six members. Four of the members have a child with an intellectual disability or autism, another supports a sibling and one member used to be an education support worker.

While all are IHC members, few of the families use IHC services. But Chalyce says all the members believe in people being able to fully access their communities. "We are all in this new way of thinking around inclusive practice, choice and having the same rights as everyone else."

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