

# Community MOVES

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**ihc**  
IN YOUR COMMUNITY

# Personally speaking

Over the years much has been achieved to improve the lives of people with intellectual disabilities. We know that people still have poorer access to appropriate healthcare, get a worse deal in the justice system, are far less likely to be employed and are far more likely to live in poverty.

We know this because we are committed to ensuring people with intellectual disabilities are counted and valued like everyone else.



Recently we all completed the New Zealand Census and IHC was involved with a number of initiatives to ensure as many people as possible could fill in their own forms. We made sure our staff had access to a number of resources, including a step-by-step guide to filling in the forms, visual and Easy Read guides and that staff were on hand to support people.

Last year we ran focus groups and conducted our own significant survey gathering opinions on a wide range of topics from more than 650 people with intellectual disabilities, their friends, family members and people who work in our sector. This year we will be concentrating on a few particular areas that will inform our advocacy work.

We also are currently having discussions about the ways membership organisations are evolving and engaging with their wider communities, and I would like to draw your attention to the membership renewal forms 2018–2019 included in this edition of *Community Moves*.

Finally, I would like to personally pay tribute to Sir Roderick Deane, who recently stood down as Chair of the IHC Foundation. The Foundation is an independent charitable trust that distributes grants to organisations supporting people with intellectual disabilities. Paul Baines, who has been a trustee of the Foundation, is taking up the role of Chair.

Ralph Jones  
IHC Chief Executive

# Sir Roderick stands down as IHC Foundation Chair

Sir Roderick Deane, Chair of the IHC Foundation, recently stood down. He is replaced by Paul Baines, a businessman and former investment banker who has served on the boards of some of New Zealand's largest public, private and not-for-profit organisations.

Sir Roderick has had a very close involvement with IHC and with the IHC Foundation for many years. He is, with his wife Gillian, Joint Patron of IHC New Zealand Inc. He is a past National President of IHC and a New Zealand Life Member of IHC.

“Being part of IHC since 1976 and, in particular, being part of the IHC Foundation since its establishment, has been both a privilege and an honour,” Sir Roderick says.

The IHC Foundation was established in 1983 as part of IHC NZ to be a means of raising funds that could be used to benefit everyone with intellectual disabilities, not just those receiving IHC services.

In 2007 the Foundation was relaunched as a charitable trust separate from IHC NZ, with Sir Roderick as its inaugural Chair. The Board of IHC NZ saw this as the best way to provide effective custody of



Outgoing IHC Foundation Chair Sir Roderick Deane

charitable funds and the best way to honour its commitment to people with intellectual disabilities.

“IHC NZ is one of New Zealand’s finest organisations and the Foundation is now an excellent charitable trust in its own right. Its creation showed both foresight and courage on the part of IHC and those of you who lead it. Gillian and I wish you all the very best for the future,” Sir Roderick says.

“It has been a great journey and fulfilled one of my long-term aspirations for IHC to broaden its scope in the charitable arena and beyond its own membership. I commend IHC for its willingness to go down this route.”

Sir Roderick says that he and Gillian have always been strongly committed to the inclusive philosophy of IHC to ensure that all children and people with intellectual disabilities are able to lead normal lives in the regular community and build upon their talents. “The Foundation shares fully this philosophy and its underlying inclusiveness.”

IHC has made three endowments to the Foundation of close to \$19 million. These funds form the capital base of



IHC Foundation Chair Paul Baines

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**COVER IMAGE:**

**Kaleb Hohneck has fun in an inflatable soccer ball at the New Zealand Williams Syndrome Association’s camp in Rotorua last year.**



# It was the right time for new friends

It has been many years since IHC Volunteering had a home in Nelson but it was the right person, right demand and right time to move the programme back to the Tasman region at the end of last year.

"We had received interest from Nelson; we had an opportunity with a coordinator who could hit the ground running. It all aligned," says IHC National Volunteering Manager Sue Kobar.

Although the programme's relaunch in Nelson is in the early stages, there has been considerable interest with a number of volunteers already signed up. This is not surprising given the extensive research and communication that is undertaken before entering a new area. Sue also credits this success to Nelson/Marlborough Volunteer Coordinator Jane Peoples.

Jane has been a Volunteer Coordinator with IHC for four years. "I've always been of the mind that it's good to give back to your community," says Jane.



Nelson volunteer Phoebe Gerry is keen to help create inclusive communities through IHC's Volunteer Programme

"It's important that young people and vulnerable people have others they can trust and talk to. It's not paid, it's a real friendship and they have each other's back."

The programme has attracted a number of students from Nelson College for Girls. Although interest from such a young age group was surprising, Jane says this is testament to Nelson's strong sense of community.

Phoebe Gerry, a Year 13 student and volunteer, believes that inclusion is a key path to success for everyone, and that IHC's Volunteering Programme can offer that.

"From Years 1 to 6, I was at a school with only 90 people, and in my year there was a student with autism. Seeing him grow from the first day of school until now has been amazing. He has flourished. Being a small school, we were involved in each other's lives and no one was isolated. This has enabled him to achieve, and I want anyone to have that opportunity."

Jane echoes this sentiment, "Friendship opens people up to a whole world that they wouldn't have seen otherwise. Friendship is important for everyone."

## Sir Roderick stands down as IHC Foundation Chair

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the Foundation and are invested to provide money for grants. The value of the investment portfolio passed the \$27 million mark at the end of February 2018.

Since 2007, as well as substantially growing the capital base, the IHC Foundation has made grants totalling \$3.9 million to a variety of organisations working to benefit people with intellectual disabilities and their families. In the year ending March 2018 it made grants to 33 organisations totalling \$970,000.

**New IHC Foundation Chair**

Paul Baines has held a range of governance positions over the past 25 years. He is currently a director of the Todd Corporation and is on the boards of the Chamber Music New Zealand Foundation and the New Zealand Institute of Economic Research. He is Chair of the Gillies McIndoe Foundation and the Gillies McIndoe Research Institute. Paul has been serving as an Independent Trustee on the IHC Foundation Board since October 2010. In 2013, he received an Honorary Doctor of Commerce degree from Victoria University of Wellington.

Paul is an enthusiastic supporter of IHC NZ and the Foundation's role. "On behalf of the Foundation Board I wish to acknowledge Sir Roderick's outstanding contribution over many years. His involvement, support and guidance has been invaluable," Paul says.

The vacancy on the Foundation Board is to be filled by Bevan Wallace, the Executive Director of Morgan Wallace, business strategists. His career spans investment banking, stockbroking, funds management and financial consultancy.

# Bikes find a new home in the playground



IDEA Services Bike Project Team (at the back from left) Matthew Fawlks, Richard McKay, Kelvin Lott, Nick Conaghan, Mark Cook, and Lynett Williams, present restored bicycles to Matura School pupils. Photograph: Ashleigh Martin, The Ensign, Gore.

Matura School students now have 12 extra sets of wheels thanks to Invercargill Bike Doctor Tony Tresidder and his magnificent team of bicycle repairers.

In mid-March, members of the IDEA Services Bike Project team donated 12 recycled bikes to the decile 2 school for the use of its students.

Matura School Principal Susan Dennison says she is thrilled with the bikes and privileged to have the association with IDEA Services.

She decided that the best way to use the bikes was to have them available in the playground for the use of all children. They will also be available at weekends and, in case anyone thinks they might disappear, she says they will be

brightly painted and labelled with the Matura School name.

Now all she has to manage is the speed of the bikes around the playground – “But it’s a nice problem to have,” she says.

The Bike Project, supported by the IHC Southland Association, works with unused and damaged bikes donated by the community.

It has been a very successful initiative for IDEA Services. Since it started in mid-2011 more than 200 bikes have been distributed to local charities, low-decile schools and community organisations in Invercargill and the Southland district, says IDEA Services Manager Jo Fredericks-Rizzi. It has also enabled many people with disabilities to learn how to maintain and repair bikes.

They carry out a schedule of repair tasks, including unscrewing bolts, removing brake cables and hand grips, dismantling and assembling bikes, cleaning down brake blocks, fixing punctures, oiling chains, and washing or painting bikes. Jo says there are around five or six people regularly working on the bikes every Tuesday and Thursday.

Renovated bikes are then checked over by the Bike Doctor and given a “warrant of fitness” before being presented to schools, churches and other community organisations – usually by members of the Bike Project Team. Jo says this has been a fantastic way for people with disabilities and IDEA Services Invercargill to connect with and contribute to the local Southland community.





## Rural health teams urged to lead the way

Health professionals in rural areas have been urged to lead the way in providing quality health care for people with intellectual disabilities.

Carolyn Stobbs and Lizzie Waring of IHC's Community Advocacy team told participants at the National Rural Health Conference in Auckland earlier this month that people with intellectual disabilities have poorer health and lower life expectancy than the general population but rural health professionals were in a position to turn that around.

"We know that continuity of care and strong relationships are essential to improving the health outcomes of people with intellectual disabilities. Healthcare professionals in rural areas are well connected to their communities and therefore are uniquely placed to lead the way in the provision of quality health care."

Carolyn, Team Leader of the IHC Community Advocacy Programme, says IHC is keen to improve understanding about intellectual disability and to encourage

better relationships between health professionals and the person seeking care, rather than decisions being made through those supporting the person.

She says GPs and other health professionals may not have had much exposure to intellectual disability in training and professional development, so IHC community advocates are keen to work with rural health teams to hold workshops and to offer training materials that could be used by students on placements in rural areas and in training rural locums.

Their presentation to conference delegates, including doctors, nurses, allied health professionals and administration staff, focused on how rural general practices could reduce some of the barriers faced by patients with

intellectual disabilities. Difficulty in communicating could be dealt with by longer appointment times and the use of more visual cues. Anxiety over appointments could be helped by scheduling appointments early in the day before the waiting times became too long.

Carolyn says a significant barrier is the issue of consent for medical procedures. It is important for patients to be able to make their own decisions about treatment, as far as possible.

She says health 'passports' are useful as they contain information about the person seeking care and how best to communicate with them. And routine annual health checks for people with disabilities have been shown to identify twice as many clinical needs as standard GP care in the course of a year.



IHC has been supporting Sam Kirk (right) since he was 17 months old. Sam lives in the Wairarapa and is a regular visitor to Chris Engel's dairy farm in Carterton.

# Public recognition long overdue for artists



IHC Art Awards Ambassador Dame Denise L'Estrange-Corbet with Shin Young Park at the Kingswood Vocational Centre in Auckland.

Dame Denise L'Estrange-Corbet is calling on public and private organisations to consider art projects and collaborations that honour the talent of artists working outside the mainstream.

Denise, Director and co-founder of WORLD fashion house and IHC Art Awards Ambassador, says it's time for disabled artists to get the public recognition they deserve. "I would love to see these artists set projects by multinational corporations, whereby they could create large pieces for foyers of buildings, or even local councils using them for sculptures for our streets and parks. It is about inclusion not exclusion," she says.

Denise became involved with the IHC Art Awards in 2009 as a

judge, then in 2016 she became an Ambassador. In this role she visits artists in studios throughout the country and sees the art they are producing. "I want to communicate with them the importance of art and how crucial it is for them to be able to express their thoughts and feelings through their work, regardless of the medium they work in," she says.

"It would be wonderful if people could see their work in large areas and be able to not only appreciate it, but understand more about the artists," she says. "And the money would go towards funding the continuing art process. In a perfect world."

Denise says there is a need for recognition within the art fraternity

too. "I would love to see people with disabilities collaborating with mainstream artists on projects and creating designs for everyday items like t-shirts and tea towels. We are living in a time where we are more socially aware than ever before, particularly with including diverse groups within our society – and this is long overdue with people with disabilities.

"It is not asking for charity; their work is incredible, and if only people would think about approaching them first when looking for a new piece of art for their home or office, they would be amazed at the quality of work they have to offer and how much pride it creates for the artists when their work is acknowledged.

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# The other mothers knew

Doctors told Denise Bray that her 18-month-old daughter was vomiting because she had a virus. But it was the mothers of other children with Williams syndrome who told her what was really going on.

Denise says it was the family's first time at a New Zealand Williams Syndrome Association family camp. "My daughter was 18 months. She was just on solids and she was vomiting all the time, and about three mothers said: 'She'll have celiac disease – get her tested'."

So Denise did get her tested and the doctors confirmed it. "They said she had severe allergies and she was probably allergic to several things, but she definitely had celiac disease."

No one understands what it's like to raise a child with an intellectual disability better than other families struggling with the same issues. Intellectual disabilities, such as Williams syndrome, aren't always well understood at the local medical centre and it's often other parents who can throw the lifebelt at the right time.

"Because it's quite a rare condition, the doctors in New Zealand often don't know much in terms of day-to-day support. You get it from other parents," Denise says. "Sometimes other parents can give you that invaluable advice as to what they have done."

The IHC Foundation makes it a priority to fund organisations that support families. Top of its list of five priorities for funding are projects that build family networks and support access to information.



Finn Wickham, Reagan Todd, and Lania Vaireka hang out at the playhouse at the New Zealand Williams

The Foundation has contributed funds towards the New Zealand Williams Syndrome Association's biennial conferences since 2012. The conferences alternate between the South Island and North Island to make it as easy as possible for families to attend. As many as 30 families come to the camps to participate in educational and support forums and to hear visiting experts provide updates on the latest research, treatment and support strategies. The Association has between 80 and 90 members.

"Conferences for parents and caregivers and people with disabilities can make a huge impact through the sharing of information, resources, strategies and experiences," says IHC Foundation Chair Paul Baines.

The New Zealand Williams Syndrome Association's most recent conference, in Rotorua last

year, featured Dr Melanie Porter, a senior clinical neuropsychologist at the Centre for Atypical Neurodevelopment at Macquarie University in Sydney. She is a specialist in Williams syndrome, Down syndrome and autism – and her research now includes New Zealanders as well.

The Association invited American developmental psychologist and author Dr Karen Levine to its conference in 2015. She camped on site and spoke to families about how to coach children out of the phobias and anxieties they often experience – how to deal with the noise of thunder or even the lawnmower.

Rett New Zealand is another parents' group that has benefited from IHC Foundation funding. Since 2012 the Foundation has contributed funds towards the Rett New Zealand Trust's biennial conferences, which



# what was really going on



Syndrome Association's camp in Rotorua last year.

regularly feature American Rett education specialist Susan Norwell along with local medical specialists. Rett syndrome is a neurodevelopmental disorder that almost exclusively affects girls and has a profound effect on their ability to communicate. Susan Norwell has introduced New Zealand families to eye-gaze technology that allows them to communicate with their eyes.

Rett New Zealand conferences offer individual consultations between families and local and international experts, lectures on genetics, discussion groups and practical sessions on caring for someone with Rett syndrome.

At this year's conference in Auckland in May, Susan Norwell will talk to parents and teachers about learning to read and write through eye-pointing and will hold individual lessons with girls and their families.

Rett New Zealand Trust Chair Dugald MacBrayne says some girls with Rett syndrome can speak, but most cannot. "The ultimate cruelty is that some speak and then lose the ability to do so. Susan Norwell is a specialist in communicating with non-verbal children." He says the eye-gaze technology has opened new horizons for the girls and their families.

Auckland paediatrician Dr Rosie Marks, who works at Starship Hospital's Developmental Paediatrics Service, will also be available for individual appointments during the conference.

Dugald says about 40 families attend the conference. Some bring their daughters, but not all the girls can travel. "It's a huge networking opportunity for parents. It also allows people from Southland, Northland, all over the country, to meet people with the same problems and who think the same way."

Dugald says it's costly for parents to travel to Auckland, but the Rett New Zealand conference itself is free, thanks to support from the IHC Foundation, the Deane Endowment Trust and other sponsors.

A third parent-led organisation receiving support from the IHC Foundation is Fragile X New Zealand. Since 2015 it has received three grants from the Foundation to run its 'No Longer Fragile' workshops in schools. The workshops – usually held five or six times a year nationwide – are run in schools where there are children affected by Fragile X syndrome. The workshops are delivered free and their aim is to build inclusive communities.

Fragile X Executive Director Andrea Lee says that despite Fragile X being the leading inherited cause of intellectual disability internationally, and easily diagnosed by a blood test, the genetic condition is not well known in New Zealand.

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Christine and Dugald MacBrayne make a point of taking their daughter Mandy everywhere with them. Mandy, 36, has Rett syndrome and Dugald says the condition is by its nature isolating because of the inability to communicate.



Everyone has a job. Joh Lomu (right) with her sisters (from left) Hola and Cilla and her children Alyssa and twins Jacob and Steven.

## Joh's huge blackboard says it all

A huge blackboard covers one wall in Joh Lomu's kitchen. It's labelled 'Command Centre' and displays the days of the week in columns, listing what needs to happen each day and who needs to be where.

On another wall hangs a more detailed schedule that records all the family activities hour by hour. To make their daily lives work, the family's timetable has to run like clockwork.

Just over a year ago, Joh's mother died and her three sisters – Falahola, 20, Alice, 15, and Priscilla, 13, came to live with Joh and her partner Axel, daughter Alyssa, 10, and three-year-old twins Steven and Jacob in their

three-bedroom house in Levin.

Joh's mother, Ofa, had been experiencing serious health problems and was moving in too so Joh could take care of her. But in January last year, only three days after being released from hospital, Ofa died and Joh became caregiver for her younger sisters. And that also meant providing full-time support for Priscilla (Cilla) who has an intellectual disability.

Joh says it was the natural thing to step into the role and her mother had prepared her for it. "I am the eldest so you automatically have that role as the eldest sister. She always made me the next mother figure, ever since I was Alyssa's age."

Joh works as a caregiver at the Summerset by the Ranges retirement village in Levin and Falahola (Hola) works in catering at Tatum Park. They take turns with the meals and getting the children to and from school, working around Joh's shifts – four days from 7am–3pm, two days off, then four days from 3pm–11pm.

Hola gets everyone up and going in the morning when Joh is on the early-morning shift. When she is on the afternoon shift, Joh starts dinner before going to work and Hola does the school pick-up.

Everyone has their chores to do after school, including the twins. And, yes, there's a job chart on the kitchen wall for that too. Only once their jobs are done do





Cilla is in Year 9 at Waiopahu College in Levin. She goes with her sister Alice.

the children get free time until dinner. "I make sure everyone has to help out, including these boys – whatever they can manage at their age."

Joh says Cilla loves doing her chores – particularly vacuuming the floor. "We went to camp one time and all she wanted to do was to vacuum the whole place. I said I don't think you know how big it is."

Alice is at Waiopahu College in Levin and is often on hand to walk with Cilla, who started at high school this year and finds it hard to cross the road. But when Alice has sport after school, Cilla has to find her way and Joh says she is settling in and becoming more independent.

Joh says there has been an adjustment to make. "It's different for us because we are her sisters.

We would have arguments and we would have fights. And I forget sometimes that she doesn't know certain things. I have to remember that there are certain things she cannot do and cannot understand."

Joh says it's at night when she has time to worry about how she's going to manage to do everything – "all the time when I go to bed. But it has to be done". She knows it's the best option – "just being together, that we are not all split up and we will just always be close".

Cilla was referred to IHC for a 'Take a break with us' Pamper Package by the Special Education Needs Coordinator at Taitoko School at the end of last year. Cilla was finishing her final year at primary school and about to start at Waiopahu College.



Joh says the gift was perfect as it helped to pay for some more "big-girl clothes" for Cilla as they got her ready for high school.

The 'Take a break with us' Pamper Package was funded by the Zena Elsie Orr Charitable Trust, which supports families who have members with intellectual disabilities.



# A community where everyone

The cups go on at 6.30am in the Barrows' milking shed at Dannevirke and that's the job done for the day. Vaughan Barrow has been milking his Kiwi-cross herd only once a day now for the past two seasons.

That means Vaughan and his wife Diane have more time to take a breath – if you can say that with 12 children. But the kids help with milking at weekends.

The Barrows farm 120 hectares of land at Maharahara, south-west of Dannevirke with the Ruahine Ranges as a magnificent backdrop. "I think the view is worth more than the land," Vaughan says.

They winter between 270 and 280 Friesian-Jersey-cross cows and raise around 75 to 80 calves each season. And every year for as long as Vaughan can remember they have been donating a calf to IHC – and before that his Dad, Peter, always donated a calf. "I don't know when it started, but we carried on."



(Back row, from left) Nick, Monique, Daniel, Anne and Thomas. (Middle row) Maria, Trudy, Ruth, John, (Front row): Philip, Gemma and Jacinta. The twins are Monique and Daniel, Thomas and Maria, John



Maria Barrow posed for her sister Anne's winning photograph in this year's IHC Calf Scheme Photo Competition.

Vaughan says his Dad's brother, John Henry, had an intellectual disability because of a deficiency in a thyroid hormone and died young in 1960. For Vaughan and Diane their donation comes from their sense of community and making sure everyone has a place and is valued for who they are. That's why, Vaughan says, when he sees a nice big bull calf he earmarks it for IHC.

Diane says people with disabilities contribute to the dynamics of the community and have much to teach society about love. For the Barrows their community extends beyond the family to the



# belongs



Diane and Vaughan, and Gemma, and Philip and Jacinta.

local schools and to their church, St Joseph's Catholic Church in Dannevirke.

Vaughan is one of five Barrow boys, and there is plenty of extended family farming in the area. He decided to make the switch from twice-a-day milking a while back, and the advice then was to move away from a Friesian herd, so Vaughan started developing a Friesian-Jersey-cross herd, known as the Kiwi cross. "I have been breeding towards it for the last 10 years," he says.

Vaughan and Diane Barrow are also experts at producing twins – the human kind. Diane has a



Maria Barrow's winning photograph of a Jersey calf.

hereditary gene for fraternal twins and has given birth to four sets of girl-boy twins. "My Mum had one set of twins and her Mum had three," Diane says.

Vaughan and Diane have seven daughters and five sons. "Of the five boys, only one hasn't got a twin sister," Vaughan says. "Nick thinks he is pretty special." Six of the children are at Ruahine School, three are at Dannevirke High School, two are at the University of Waikato and one is dairy farming in the Waikato.

There is an artistic gene in the family too that Diane says comes from Vaughan's side of the family. Daughter Monique has covered the hallway in murals, Anne and Monique won book vouchers in the IHC Calf Scheme colouring competition in 2011, and Trudy, Anne and Maria have all won Prezzy cards in the IHC Calf Scheme Photo Competition – Trudy in 2016 and Anne and Maria last year.

## Farmers raise \$1.4m

Last season 3561 dairy farmers raised more than \$1.4 million for New Zealanders with intellectual disabilities through the IHC Calf & Rural Scheme.

That's a total of more than \$35 million in the 33 years that the Scheme has been running.

Farmers are able to donate a real calf, a 'virtual' calf (donation of \$300) or an average price (from the sales). They may also donate cull cows, bobby calves and other stock. 577 farmers pledged more than one calf.

In the 2017-18 season IHC received 4343 pledges.

These pledges were made up of:

- **3222** calves
- **510** virtual calves
- **264** donations
- **221** average price
- **25** cull cows
- **9** sheep
- **92** others – usually bobby calves or calves that are being grazed on for 2–3 years.



2016 photo competition winner Trudy Barrow lined up her brother John watching the silage contractors on their neighbour's farm, with a view of the Ruahine Ranges behind.

## Public recognition long overdue for artists

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"I am always amazed at the quality and variety of work produced each year from painting, needlework, pottery, knitting, woodwork, papier-mâché. I have seen artists who enter the IHC Art Awards each year and they have really carved out their signature now. I can identify them by their work, as you can with any artist in paint, fashion or writing," she says.

"In 2009, when I was first asked to judge the IHC Art Awards, I had absolutely no idea what an impact not only the art, but the artists would make on me. It is something I so look forward to each year when I travel the country to meet all the different artists, view their work and see the facilities they work in. They are just the most beautiful people I have ever met, and their work never fails to amaze and inspire all who see it."

This year, Denise has visited artists in the IDEA Services Kingswood Vocational Centre in Auckland, The White Room Creative Space in Christchurch, the IDEA Services Arts on High gallery and studio in Lower Hutt and Whanganui Creative Space.

Entries open for the 2018 Art Awards on 1 May and close on 31 May. They are open to artists with intellectual disabilities living in New Zealand. The national exhibition will be held at Arts on High in Lower Hutt from 9 July to 6 August. The IHC Art Awards Gala Night is on 26 July.

## Tauranga launch for multimedia show



Jess, 28, and Sunil Fernandez Richie, 24, and their daughter Carmen, 2, from Waikato, feature in the 'Take a moment with us' exhibition. Jess and Sunil, who both have disabilities, have support to care for their daughter.

This winter visitors to Tauranga will have a chance to see what it's like to live with an intellectual disability.

The multimedia show, 'Take a moment with us', opens at The Incubator Creative Hub in July. The show introduces people to Kiwis with intellectual disabilities. It features photographs by Christchurch documentary maker and photographer Bridgit Anderson and video footage shot and edited by Sam Morrison, Tania McKenzie Bellam and Jasper O'Donnell.

The exhibition is open to the public from Wednesday 18 July until Sunday 5 August.

Bridgit, Sam, Tania and Jasper have shot film in Auckland, Christchurch, Waikato, Wellington and Manawatu – and the result is a showcase of people with intellectual disabilities from every walk of life. The exhibition captures people within their communities and encourages

visitors to think about what life is really like when you have a disability and what it could be like if communities were open to including everybody.

Bridgit Anderson is a visiting lecturer in photography at the School of Fine Arts at the University of Canterbury. She has shown her work in both New Zealand and the United Kingdom.

Sam is a former IHC National Self Advocacy Coordinator. He is an artist and has a Master in Fine Arts from the Auckland University of Technology. Tania is a videographer and photographer and works as a Digital Media Producer at IHC. Jasper is a Wellington videographer.

The exhibition will be at the People's Gallery at The Incubator Creative Hub in Tauranga. The gallery is at The Historic Village, 17th Avenue, Tauranga.

To find out more about 'Take a moment with us', contact Danette Wilson at [danette.wilson@ihc.org.nz](mailto:danette.wilson@ihc.org.nz)



## The other mothers knew what was really going on

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Andrea says her 13-year-old son was diagnosed at the age of three. "It was life-changing for us because we suddenly had access to information that explained many things we had struggled to understand about Andre. And it made a big difference to know a little of how he might be experiencing the world, about his sensory sensitivities and high anxiety."

She says the condition has been widely studied and a lot is known about the neurobiology of the condition. "We understand what is happening in the brain and the impact that has on learning." This information is shared through one-hour workshops in pre-schools, primary schools and high schools.

"Instead of everyone having to research every time a child with Fragile X comes along, we go out to them and we individualise the information to the child, working together with the whanau and school community."

A request for a workshop usually comes from the family, and after preliminary discussions with the family an approach is made to the school. The aim is to build a partnership between the family and the school. "Hopefully, it supports and deepens the relationship the family already has with the school."

Andrea says it's about letting people see the world through the eyes of someone with Fragile X and saying, "These are the things that will help the child or young person to be successful in your community".

"One of our aims is to show people they are not dealing with children who are choosing to behave badly." Andrea says if a child is highly anxious they are unable to process what is being said. However, if the child can be supported to self-regulate then they can learn.

"What we are trying to say to people is when a child or an adult is in that state, that is compromising how they function. We are keen to send a positive message that people with Fragile X are really capable people, given the right support



Fragile X Executive Director Andrea Lee reading with her son Andre.

and opportunities to learn and develop skills."

There is a high demand for the 'No Longer Fragile' workshops, but they are limited by cost and by the availability of those who are trained to deliver them. Andrea says there are already four lined up for 2018 with people who were on waiting lists last year.

Her son, Andre, now in Year 7 at an inclusive mainstream school, has made big progress. "We have been able to share with the school how he learns – what we call the Fragile X learning style. For example, we know that he learns visually and simultaneously, not sequentially. It has changed the way he has been taught to read." She says students like Andre learn better if they can see the whole picture, rather than the learning being broken down into parts. "We know that visual applications work very well for helping students to learn to spell, for example, and he is very motivated by the use of technology."

IHC Foundation Chair Paul Baines says more parents are looking for support directly from parent-led groups that are focused on a particular syndrome or condition, where there is a strong community of interest and shared understanding of the challenges they face. IHC has always supported, and will continue to support, groups that can create effective support networks.

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### **IHC NATIONAL OFFICE**

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

### **EDITOR**

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

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