

# Community MOVES



FAMILIES SIGN UP FOR WILLIAMS SYNDROME STUDY – PAGE 3

NEW GUIDES FOR LAWYERS SAFEGUARD VULNERABLE PEOPLE – PAGE 9

GENE TEAM SEEKS ANSWERS FOR MORE FAMILIES – PAGE 10

BEN TAKES A BOOT-CAMP CHALLENGE – PAGE 15

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IN YOUR COMMUNITY

# Personally speaking

We are operating in a time of extraordinary pressure on disability services. In the past couple of months there has been quite a bit of media coverage on the estimated \$150 million funding shortfall in the disability sector, identified by the New Zealand Disability Support Network (NZDSN).



NZDSN commissioned Deloitte to conduct the independent research, and it found that people with disabilities are at risk due to underfunding, with a 12 percent gap between funding provided by the Government and the real cost of support. Associate Minister of Health Julie Anne Genter also said the disability sector was at breaking point.

This comes at a time when providers like us are working hard to innovate and provide more flexibility and choice for people in line with the Government's Enabling Good Lives principles. IHC and IDEA Services are proud members of NZDSN and we are all working together to ensure realistic funding for individuals with disabilities. We await the Government's 2019 Budget with interest.

The IHC Board and Executive Group met at the end of February and considered these pressures on the sector and our responses to them. The Board affirmed its ongoing commitment as an organisation to people with intellectual disabilities and their families but will consider other opportunities that benefit the wider organisation.

We are committed to providing quality services to people with intellectual disabilities, whether they require 24/7 support or wish to engage with us for other services in line with their Enabling Good Lives plans. We are finding new ways to engage with young families and the next generation. Last year we sent more than 600 free books to families with new diagnoses and engaged with more than 100,000 people through our social media campaigns. We also took a good look at our membership to consider what a modern membership organisation looks like. This year we have increased our membership by 20 percent – and many of those new members are younger families and people keen to support us on campaigns for change.

This edition of Community Moves contains membership forms – if you aren't a member, please consider joining. Or if you know someone who would like to be better connected with us – please feel free to share the forms with them.

Ralph Jones  
IHC Group Chief Executive

# Families sign up for Williams syndrome study



Children between the ages of two and seven years with the rare genetic condition, Williams syndrome, are being enrolled in an Australian research project to track their development over time.

New Zealand children with Williams syndrome and their parents are participating in an Australian study to track the children’s development and the experiences of their families.

It is a longitudinal study, which means the families have the opportunity to participate over a long period of time to allow researchers to gather as much information as possible about the rare genetic condition and its impact.

The study is led by Associate Professor Melanie Porter, a Senior Clinical Neuropsychologist from Macquarie University in Sydney, and PhD candidate and clinical neuropsychology intern Jessica Reeve. Both researchers came to the New Zealand Williams Syndrome Association camp in Christchurch in January, where they discussed the research project and conducted interviews with parents and assessments of children.

Jessica says they have enrolled 10 New Zealand children between the ages of two and seven years in the project, which involves a face-to-face assessment with each child. They are looking at how early neuropsychological functioning and learning processes contribute to later intellectual, adaptive, academic and

mental health outcomes for children with Williams syndrome.

“It’s quite comprehensive, so it does look at the whole development of the child. We also look comprehensively at the parents – parent coping, parent mental health and parental attitudes.”

She says they are keen to discover what predicts later development, allowing for the development of interventions for both children and their parents. Melanie and Jessica hope to track the children over two, five, 10 and perhaps 20 years.

Melanie says it is of benefit to be able to include New Zealanders in the study. “We think that there are probably 350 people who have been identified with Williams syndrome in Australia. We have about 200 on our research database,” she says. “The more numbers you have, the more you can understand the condition.”

The New Zealand Williams Syndrome Association holds a summer camp every two years. It is a lifeline for the families, who can connect with each other, share advice and experiences and hear from experts about the latest research. It has between 80 and 90 members and around 30 families attend the camps. Melanie and

...continued on page 4

## CONTENTS

- Page 3 Families sign up for Williams syndrome study
- Page 4 Views canvassed on minimum pay
- Page 5 Fans come one step closer to their dream
- Page 6 Members have the chance to bring change
- Page 7 The distance is short between friends
- Page 9 New guides for lawyers safeguard vulnerable people
- Page 10 Gene team seeks answers for more families
- Page 12 High Street artists add colour to shopping strip
- Page 13 Family’s break was a time to heal
- Page 14 Researcher backs special courts for young adults
- Page 15 Ben takes a boot-camp challenge

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**COVER IMAGE:**

**Keelan Ward and his family renewed friendships at the New Zealand Williams Syndrome Association camp at Living Springs, Christchurch, in January. See story this page.**



...continued from page 3

Jessica both gave presentations during the weekend.

“Jess spoke about her pre-school study. I spoke about anxiety across the life-span and self-care for carers.” Melanie says about 50–60 percent of people with Williams syndrome are diagnosed with anxiety at some time in their lives. The figure is 5–6 percent for the general population – “so it’s 10 times greater”.

Melanie says the latest research on Williams syndrome shows how much it varies from person to person. “There is considerable variability in just about every aspect. Williams syndrome involves a number of genes that have been deleted on chromosome 7, usually about 26 to 28 genes. Although some individuals with Williams



Macquarie University researchers in Sydney hope to track children with Williams syndrome over two, five, 10 and perhaps 20 years to discover what predicts later development.

syndrome might have eight genes deleted, some might have 32,” she says. Aside from genetic factors, environmental factors too play a part in this variability.

If you have any questions about the research, or want to participate, please contact Jessica Reeve at [jessica.reeve@mq.edu.au](mailto:jessica.reeve@mq.edu.au)

## Views canvassed on minimum pay

IHC is pleased that the Government is looking into replacing the Minimum Wage Exemption permit with a wage supplement to ensure people with disabilities are paid at least the minimum wage.

The scheme was introduced for employees who have disabilities that limit them carrying out their work. Labour inspectors can issue the permit in certain circumstances, giving the employee a rate lower than the minimum wage.

IHC Director of Advocacy Trish Grant says it is discriminatory for people with disabilities to earn very little for working hard. “People with intellectual disabilities deserve the same right to earn the minimum wage as other people – fair pay for fair work,” says Trish.

“It was disturbing to find out that

some people were earning as little as 89 cents an hour.”

Between February and April, the Ministry of Social Development and Ministry of Business, Innovation and Employment have been carrying out consultations with the disability sector.

Minister for Disability Issues Carmel Sepuloni says around 900 New Zealanders have a Minimum Wage Exemption permit – with more than 70 percent earning less than \$5 an hour.

“We’re proposing a wage supplement approach that continues to provide disabled workers with job security and rewarding work, while ensuring every working-age New Zealander receives at least the minimum wage,” she says.

Minister for Workplace Relations Iain Lees-Galloway says the consultation is about looking at ways the Government can support employers to take on workers

with disabilities, rather than a system that penalises people with disabilities because they want to work.

But people working for less than the minimum wage are not willing to speak up until they are confident they will not be worse off. IHC Self Advocacy Advisor David Corner says he’s heard from families who are worried about how it will affect them.

“Will people with intellectual disabilities be better off under these changes? Many of these people receive the benefit, and they’re unsure if this would be reduced or even taken away if they were to earn the minimum wage.

“We need to make sure that if a worker goes off the benefit, they will be able to get back on it if things change and they can no longer work.”

Trish says any change needs to ensure more people with intellectual disabilities can enter the workforce.

# Fans come one step closer to their dream

Their ultimate goal is to perform on the world's biggest and most prestigious kapa haka stage. And Wairarapa group Te Roopu Manaaki, came one step closer by scoping out the national competition at this year's Te Matatini event in Wellington.

Te Matatini Chief Executive Carl Ross gifted the roopu 23 tickets to one of the day's performances. Even the capital's rain and wind couldn't drown out the spirits of the team who, despite having to climb higher into the stadium to avoid getting wet, had an amazing time.

Kaitātaki wahine (female leader) Faith Konia says being at Te Matatini was a dream come true. "It was so cool watching our idols on the stage, the ones we look up to," Faith says.

Te Roopu Manaaki Coordinator and IDEA Services Senior Support Worker Arlene Whitney says the whole team was buzzing. "When they got back home they were watching the rest of Te Matatini on TV and were saying 'I've been there' and 'I saw that'."

The team stood out from the crowd in their bright pink uniforms and hats, and before they even entered the gate were approached by Radio New Zealand and Māori TV for interviews. Once in the stadium, Māori TV's Te Kaea programme did a live interview with Faith alongside the rest of the team.

Faith says it was really nerve-racking, but managed to get through it. "I really enjoyed it, and it was a great opportunity to represent Te Roopu Manaaki."



Te Roopu Manaaki performers arrive at Westpac Stadium in Wellington excited at the prospect of watching Te Matatini up close.

In December last year, Te Roopu Manaaki performed alongside 15 other teams at the inaugural Te Anga Paua o Aotearoa National Kapa Haka Festival in Hamilton. The event brought together more than 300 performers with intellectual disabilities, to showcase various kapa haka and waiata that were native to their hometowns.

Faith says she hopes attending Te Matatini will allow people with intellectual disabilities to be more visible. "The diversity of disability is out there. We shouldn't be in the shadows, so I hope disability gets more out there," says Faith.

"I feel when I perform on stage I don't have a disability – I feel free like any other kapa haka performer.

"To see people with disabilities on Te Matatini stage would be awesome and a privilege."

IDEA Services Kaitakawaenga (Senior Māori Advisor) Taki Peeke says it doesn't matter what ability a kapa haka performer has – the passion and commitment transcends all who do kapa haka.

For kaitātaki tāne (male leader) Caleb McNamara it would mean the world to him to one day perform at Te Matatini. It would be an opportunity to show that, despite being discriminated against, they are standing tall to tell their story.

"We decided that we wanted to have a voice and speak up for others like us," says Caleb.

The next step for Te Roopu Manaaki is to prepare for the IDEA Services Kapa Haka regionals in Taranaki. The other two regional festivals are in the northern and southern regions. Following the regional festivals, the second Te Anga Paua o Aotearoa National Kapa Haka Festival will take place in 2020 in the central North Island.



Caleb McNamara and Faith Konia were interviewed by media about their ambition to one day perform on the Te Matatini stage.



IHC Hamilton Association committee member Kama Papa (left) and Chair Jasmine Morrison participate in workshops at the IHC Annual General Meeting held in Wellington in September last year.

## Members have the chance to bring change

IHC is looking to get more people directly involved in issues faced by those with intellectual disabilities in our communities and to help them to live good lives.

Thousands of people engage with IHC every day on social media, as volunteers and as donors – but, like many membership organisations, the number of signed-up members participating in local IHC Associations has been dropping over the years as people get older and younger families seem reluctant to sign up.

In 2016 IHC set up a Member Council to create a stronger connection between members and the Board.

The Member Council is taking a fresh look at membership, with a recent survey of members and a drive to attract new members.

At present IHC has 2273 members; 65 percent are female and 75

percent have been members for 15 years or longer. IHC has set a target of 500 new members by the date of the Annual General Meeting in September this year.

For \$5 a year, IHC members have the opportunity to join an organisation they believe in and be heard on issues that concern them. They have the ability to influence direction and achieve shared objectives. IHC members can also participate in the 'Take a break with us' programme, which is available to families/whānau and carers who care for a person with an intellectual disability or autism living at home.

To help boost membership, IHC Associations have been

contacting former members and looking for ways to connect with new families. As a result, 158 lapsed members have so far renewed their subscriptions.

Member Council Chair and New Zealand Life Member Barbara Rocco says, for her, membership means that she supports what IHC stands for – a good life for people with intellectual disabilities.

“Members can be involved as much or as little as they wish but, when they join us, I see it as a sign of commitment to IHC’s aims and values. In our local communities our members are often the face of IHC. It’s a wonderful organisation with an amazing history and a strong future.”



# The distance is short between friends



(From left) IHC Nelson-Marlborough Volunteer Coordinator Jane Peoples, Carol Boswell and Samuel Claughton tried a round of mini golf together. Samuel won by two holes.

It takes Carol Boswell over an hour to drive from her home at Māhau Sound in Marlborough to Picton to see her friend Samuel Claughton.

But she has travelled far further on her adventures, and not so long ago she was sailing the high seas to China and back with her husband Brian. The pair spent 15 years sailing and living on board their 16-metre yacht before they decided it was time to come ashore.

Carol and Brian have now put down anchor at Boswells' Berth, Māhau Sound and wait for visits from the Pelorus Mail Boat. Their yacht is now moored outside.

When Carol came to the end of that adventure she was ready to embark on some new ones and started researching volunteering opportunities.

Carol, 71, and Samuel, 55, met through the IHC volunteer friendship programme in June last year. Samuel lives with nine others at the Papatuanuku

Independency Trust at Waikawa outside Picton. It's a 5.5-hectare rural property where the residents, a group of people with intellectual disabilities, grow vegetables and fruit and raise chickens and sheep.

"I do try to get there twice a month," Carol says. "I would love to get there more often; I am working on it."

Even though they are only five minutes from Picton, some of the residents of Papatuanuku Independency Trust, who don't have family or close friends in the local area, may at times feel isolated, says Trust Manager Samantha Quinn. She and local IHC Volunteer Coordinator Jane Peoples have been working hard to keep them connected with others in their community.

Samuel is keen to join in with community activities. He volunteers with the Picton Dawn Chorus to check predator traps to protect the bird life in Picton and Waikawa. "I do it on a Friday morning and on a Sunday as well.

It all depends on the actual day." He also attends the Picton Men's Community Shed.

But the days he spends with Carol are something special. "I collect pine cones and do the baking as well. I make muffins and cakes and that. We both work together."

Carol says they enjoy wandering around Picton and the marina together. "We chat about everything and nothing as we wander." She says she is working on having Samuel visit Māhau Sound more often. "It all takes organising and coordination but, once we can work out a routine, Samuel and I will have more contact."

Samantha says Carol and Samuel hit it off immediately when they first met in June last year, and it is making a difference to Samuel. "He is becoming more and more confident. He has got a bounce in his step," she says. "He has something to look forward to – he has got a friend."

# New guides for lawyers safeguard

A free online resource designed to promote fair treatment for vulnerable people under New Zealand's legal system is now available for use by lawyers and judges.

A team of disability and legal experts has developed Benchmark, a set of guidelines to protect people's rights and improve their access to justice. Benchmark is funded by the IHC Foundation and the New Zealand Law Foundation (NZLF).

The project was sparked by initial research carried out for the NZLF and published in 2014 showing that people with intellectual disabilities were not being treated fairly in our legal system. Some people detained under compulsory care orders were serving much longer sentences than if they had gone to prison, were vulnerable to pressure to confess and plead guilty, and found it difficult to be active participants in legal matters because of difficulties with communication and a failure to implement procedural accommodations.

The Benchmark project was launched in 2016 against the background of the Teina Pora case. He was compensated by the Government in 2016 for wrongful conviction and imprisonment for rape and murder after spending 21 years in prison. A factor critical to the case was the discovery that he had fetal alcohol syndrome.

Benchmark includes specific advice on fetal alcohol syndrome as well as guidance on pre-trial case management for vulnerable witnesses and working with



Leader of the Benchmark project Dr Brigit Mirfin-Veitch and visiting UK academic Professor Nathan Hughes, whose research has pointed to the high prevalence of neuro-developmental disorders among young people in custody.

court-appointed communication assistants. There are also guides for dealing with children, older adults, and people with intellectual disabilities or mental distress.

Donald Beasley Institute Director Dr Brigit Mirfin-Veitch, who led the Benchmark project and the earlier research work, says the guidelines are a collection of best practice with vulnerable people. Knowledge and experience have been shared by lawyers with an interest and involvement and understanding of the issues.

“What we want to do is to make these good practices much more commonplace,” she says. “I think we are starting to change. There is a growing awareness that we need to do things differently.”

Benchmark is inspired by the United Kingdom's The Advocate's Gateway, a set of guides used by legal professionals in England and Wales. The original developers of the British resource, Dame Joyce Plotnikoff and Dr Richard Woolfson, collaborated with local researchers on the project.



# guard vulnerable people

While the UK resource was the starting point, the Benchmark guidelines are specific to the New Zealand context. The guides apply to complainants, witnesses and plaintiffs, as well as defendants. Local experts looked at how procedural accommodations can be applied regardless of someone's role in legal proceedings.

Brigit says while the guides are more detailed than originally envisaged, this makes them particularly valuable to legal professionals, who can rely on them to show them what they can do in the current system under present legislation. Accompanying the guides is a large collection of case law for reference.

Brigit acknowledges that there is also a need for disabled people and those who support them to have access to this kind of information about what they can expect. "From a disability perspective, it's important to me to not presume that people are inherently vulnerable and to employ a light touch."

The IHC Foundation contributed \$80,000 to the project over two years and the NZLF contributed \$218,000.

The project team included Professor Kate Diesfeld and Dr Kirsten Hanna from AUT University, and Dr Emily Henderson, a Whāngārei lawyer who has conducted research with lawyers and judges on interviewing people in court.

Retired judge Anne Kiernan has supported the Benchmark project and reviewed the guidelines. She says they will assist lawyers, judges and others in properly addressing the issues that arise

when vulnerable people and children become involved in the legal process. "They are the only resource in New Zealand which combines legislative references with research sources and best-practice guidelines. A central feature is accessibility.

**"From a disability perspective, it's important to me to not presume that people are inherently vulnerable and to employ a light touch."**

"It is vitally important that consistent standards are applied in the justice system. Complainants, witnesses and defendants who are vulnerable because of age, impairment, experience, communication difficulties or any other impediment, must be able to participate fully in the legal process," she says.

"From my own experience of 20 years as a lawyer in New Zealand and then 15 years as a judge there, I would have been delighted to have had this resource on hand.

"In the UK there are registered intermediaries who are appointed by the court to assist in the questioning of vulnerable people at court. In New Zealand the law allows for communication assistance, and there is a growing practice for judges to appoint communication assistants in appropriate cases."

NZLF Director Lynda Hagen says one of the most satisfying aspects of its work is supporting projects that make a real difference to the ability of marginalised or disadvantaged social groups to navigate the legal system. "Benchmark is one of those projects, and we are confident it will make a real difference to supporting vulnerable witnesses and defendants, and the professionals who represent them, to achieve better access to justice.

"When we supported this project, we intended for Benchmark to be organic – to grow and develop as understanding of needs and issues arise and to respond to the needs of the users. The resources in Benchmark will provide a valuable source of current information to better inform the professionals who deal with these groups, and to help improve processes for the many members of society who do not have a clear voice for themselves."

Three further guides are being developed on working with people with autism spectrum disorder, mental distress and people who are hearing impaired. Brigit says she also envisages the resource expanding to include migrants for whom English is a second language and other potentially vulnerable groups.

IHC Foundation Chair Paul Baines says the Foundation is pleased to be associated with the development of such an important resource. "It provides lawyers and judges with access to advice that will help to remove barriers to vulnerable people getting a fair deal from the justice system."

Researcher backs special courts for young adults, see page 14.

# Gene team seeks answers

A University of Auckland 'gene team' has launched a new research project with 20 families to find the causes of more rare genetic conditions.

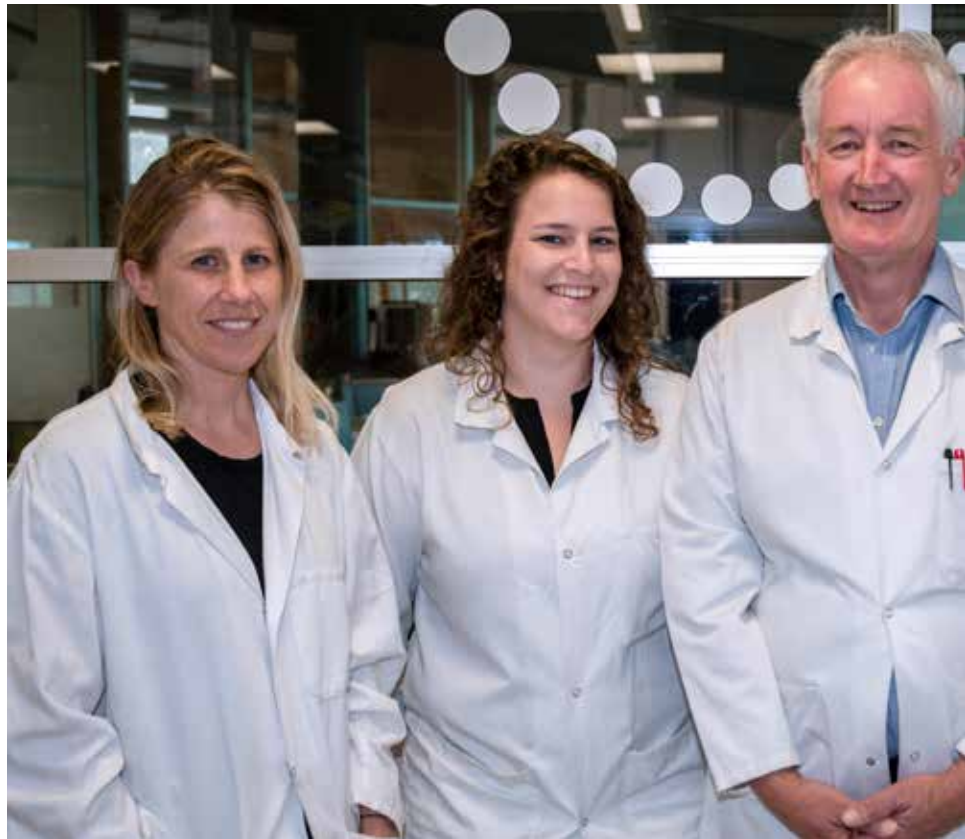
Following hard on the success of a pilot project with an initial 20 families, researchers Dr Jessie Jacobsen, Professor Russell Snell and Associate Professor Klaus Lehnert from the university's School of Biological Sciences and Centre for Brain Research are now recruiting families for their new study.

In the pilot project, from 2016 to 2018, the team was able to find the genes and mutations responsible for rare conditions in 14 children – a better result than they were expecting. Russell says the success rate of the first study means that clinicians have waiting lists of families who want to be involved. "There is a lot of interest out there – there is a major unmet need," he says.

"Our discovery rate is equal to the best groups in the world and there aren't many best groups in the world. It's because we take a lot of care with every variant and we don't apply carte-blanche filters."

These scientists are gene detectives, doing painstaking work to examine DNA and find where genes might be deleted or duplicated. Klaus, a functional biologist, works to understand the molecular mechanisms through which genetic variations cause disease. He uses computers to analyse large and complex data to identify these genetic variations.

Klaus likens his task to finding typos in a novel. The sequencing reads the families' genomes as billions of small fragments, similar to those produced by a paper



The gene team (from left) Dr Jessie Jacobsen, PhD candidate Whitney Whitford, Professor Russell Snell and Associate Professor Klaus Lehnert from the School of Biological Sciences and Centre for Brain Research. Photograph – Dr Charlotte Johnson.

shredder, then compares all individual strips of paper one by one with the whole novel to see what's missing or changed and to make sense of the story. He does this analysis with the help of high-performance computers and support systems provided by NeSI (the New Zealand eScience Infrastructure), an initiative funded by the Ministry of Business, Innovation and Employment and New Zealand's major universities and research organisations.

He says analysing genomes is computationally intense, taking around 2000 hours of computing to reconstruct an individual's genome and discover genetic variants. "Practically speaking, NeSI provides massive parallel computing resources that allow us to complete 2000 hours of computing in less than 40 hours of real time."

The process is more cost-effective than standard tests that screen gene by gene. The team screens the whole genome of the affected individual but only 1 percent of the DNA (the exome) of the parents. Sequencing the exome – the protein-coding regions – is about half the cost of sequencing the genome. The exome is thought to harbour about 85 percent of the known DNA variations that cause disease.

Many other research teams apply filters to reduce the amount of data they have to analyse, but this team doesn't because they don't want to miss anything. Russell says most families referred to the team have been through some kind of testing. "In general we are dealing with the most difficult cases where variants have been looked for and not found."

Jessie says as well as being able

# for more families



Associate Professor Klaus Lehnert from the university's School

to find answers for many of the families, the other interesting outcome from the pilot project was the range of genetic variants they found as part of the analysis.

Like the pilot, this latest research will be funded by the IHC Foundation. This time the Foundation is contributing \$197,000, which includes funding PhD candidate Whitney Whitford to work on the project.

The team's goal is to give children, their doctors and their families a diagnosis and a way forward. The researchers also want to build more evidence for their new cost-effective approach to genome sequencing that is achieving world-class results. How quickly the research translates into routine clinical practice will come down to advocacy by parents, clinicians and parent groups.

Jessie says traditional gene-

screening approaches often fail to deliver genetic diagnoses for rare genetic conditions. "This reduces hopes for future treatments, makes assessing the risk of future pregnancies difficult, and has the prospect of lengthy and costly 'diagnostic odysseys'.

"Our own research, along with international studies, has demonstrated that the now cost-effective genome-wide sequencing technologies can dramatically increase the rate of genetic diagnoses in rare conditions, all for the cost of an overnight stay in hospital."

This second project has three goals. First, to provide answers for families that will help manage their treatment. Second, that the results from these families will significantly contribute to evidence to support the use of this technology in mainstream clinical use. Third, that the gathering and cataloguing of naturally occurring genetic variations in the population will allow for a more efficient approach to identify those genes that cause rare disorders.

The team wants to do the DNA analysis as early as possible because, in some cases, it is possible to minimise the impact on the individual child. Jessie says that in the course of their research they have been able to identify in three cases the cause of a genetic condition early enough to alter the outcome of that condition.

Most participating families will be referred by their clinicians. But Jessie says families who have a child with a neurodevelopmental condition are welcome to approach them directly about opportunities to participate in the research.

To find out more, email [j.jacobsen@auckland.ac.nz](mailto:j.jacobsen@auckland.ac.nz)

## Whitney takes up research fellowship



University of Auckland PhD candidate Whitney Whitford uses an agarose gel to inspect the quality of DNA. Photograph – Dr Charlotte Johnson.

The IHC Foundation is funding University of Auckland doctoral student Whitney Whitford to work with the genetics team on its latest project.

IHC Foundation trustees are enthusiastic about the results being achieved by the team in determining the causes of rare genetic conditions and have agreed to offer an IHC Foundation Post-Doctoral Fellowship to support the work.

Whitney has just submitted her PhD at the University of Auckland and has already won awards for her doctoral research into structural variations of DNA. She has a history of engaging with the community and runs the Minds for Minds website and email interface.

Her job will be to liaise between families and clinicians, extracting DNA and processing and analysing data. It is expected that 10 families will have their DNA sequenced and analysed by September this year and the remaining 10 families by September 2020. The results of the research will be delivered to the families involved in collaboration with clinical geneticists.



# High Street artists add colour to shopping strip

In August, the walls of the Arts on High Gallery in Lower Hutt will be covered with 100 works from entrants around New Zealand for the IHC Art Awards exhibition of finalists.

But that's just once a year. Arts on High on the main Lower Hutt shopping strip is the studio where artist Darryl Kennedy and his fellow artists work year-round to create artwork and collaborate on projects that help them communicate and connect with their community.

Some of their pieces may be among the finalists that go up on their studio wall. Darryl has been selected as a finalist three times, and he will enter again this year.

Darryl tries his hand at a range of media, but he is chiefly a painter of his memories and experiences. A cruise around Australia with his sister last year is still providing a rich source of material. His vivid painting of a lorikeet was exhibited at Parliament during the Arts Access Aotearoa Awards 2018.

"Darryl focuses on his own art work. He comes here twice a week and he just uses this space to make his own creations," says Senior Support Worker and Arts on High Manager Teresa Saunders. "He will often come to us and say he wants to do a particular thing and then we will give him the materials and just allow him to express himself.

"Darryl likes putting down his art work on to canvas from memory and to show and tell people where he has been and what he has actually seen."

But Arts on High is not only a place where artists work on their individual projects. Teresa says the



Wellington artist Darryl Kennedy has made the finals of the IHC Art Awards three times.

gallery and studio is a place where people can connect with their community. One popular project was Hutt City Council's Central Hutt Art Trees Creative Christmas Tree exhibition in 2017.

"Hutt City Council approached us and asked if we'd like to paint some Christmas trees for them. We ended up with about 28 different Christmas trees, and the Christmas trees were used as part of the creative space for Hutt City Council." Teresa says the 3D-sculpted trees were exhibited along with those created by other artists.

Teresa says the artists love getting involved in local events, such as providing art to dress empty shop windows, or creating wearable art for the Pimp My Jacket Runway

Show run by MIX, a Lower Hutt-based mental health support group, for the Hutt Winter Festival last year. The jackets were then displayed in Arts on High's shopfront window.

"Window displays are a great, fun way for them to express themselves." Teresa says the more the public interact with the artists, the better understanding they have of who they are and the stigma starts to fade away. "They look at the artist and see what they actually create and they start to build a rapport. And that rapport has a knock-on effect of being included and accepted more."

Entries are open for the IHC Art Awards 2019 between 1 May and 31 May. For more information, see [ihc.org.nz/art-awards-2019](http://ihc.org.nz/art-awards-2019)

# Family's break was a time to heal



Relaxing during their Tauranga weekend break are (from left) Kawiti, Anthony, Wendy, Aiden, Jodi, Charles, Samantha and Phoebe.

Levin mum Wendy Tautari and her family took time out in February to heal and support each other after her 19-year-old son, Joseph, died unexpectedly.

Wendy, who has two children with special needs, says the family was rocked by his death in September. She says they needed to get away. They were recommended for a break through the IHC 'Take a break with us' programme and went to Tauranga for a weekend.

The family had made plans for sightseeing, fishing and swimming, but in the end, Wendy says, they mainly stayed at their beachfront holiday house and stuck close to each other. "We just hung out together. It was all about taking a break. We are very grateful and thankful for having the opportunity to go away."

Day to day Wendy manages the needs of her blended family,

which includes her husband Kawiti; daughter Samantha, 20, and Sam's 10-month-old baby Charles; Phoebe, 17; Jodi, 14; Anthony, 13; and Aiden, 7.

Jodi has a rare genetic condition called chromosome duplication syndrome. She has delayed development, struggles with motor skills and has an intellectual disability. Jodi wasn't diagnosed until she was 12 and, while she doesn't qualify for ORS funding, she now gets help under the School High Health Needs Fund. Anthony has ADHD and has times when he struggles with anxiety.

Wendy works as a support worker for ACC clients and used to work up to 50 hours a week. Since Joseph's death, however, she has had to cut her hours in half. "I just can't. Afternoons, I am a mess – well, not a mess, but I am not cooking meals."

Helping to care for baby Charles helps them all. "Absolutely. He is such a blessing."

The 'Take a break with us' programme is partly funded by the Zena Elsie Orr Memorial Trust and supported by Millennium & Copthorne Hotels New Zealand, the Waipuna Hotel and Conference Centre, the IHC Foundation and IHC donors. It is available to members of IHC.

To find out more, see [ihc.org.nz/take-break-us](http://ihc.org.nz/take-break-us)



Wendy and her son Joseph a year ago.



# Researcher backs special courts for young adults

The District Court is looking at the need for a specialist court for young adults because evidence shows that the justice system isn't meeting their needs. UK Sociologist Professor Nathan Hughes says this would directly benefit young people with neurodisabilities too, many of whom are ending up in custody.

Chief District Court Judge Jan-Marie Doogue and Principal Youth Court Judge John Walker are considering the impacts of mental illness, intellectual disability and acquired brain injury on young adult offenders with a view to making changes. They say the Youth Court has well developed processes to respond to the complex needs of young people who often have neurodevelopmental impairments, but this does not extend to the adult court, or to young adults as they transition into this system.

Nathan's research provides some of that evidence. His work examines the influence of health and developmental difficulties on the risk of criminality and criminalisation among young people and young adults, with a focus on neurodevelopmental disorders and traumatic brain injury. In March he met with Justice Minister Andrew Little, Minister for Children Tracey Martin, Children's Commissioner Andrew Beecroft, and Judge Walker.

He says effective practice with young adults requires specialist knowledge and understanding that adult court professionals don't always have.

"Young adults are physiologically different to older adults, and



Professor Nathan Hughes says working effectively with young adults requires specialist knowledge and understanding that adult court professionals don't always have. Photograph – Otago Daily Times.

typically more akin to teenagers in key aspects of their maturation. The period 18–25 is a dynamic phase of functional brain development towards the 'adult form', particularly regarding the maturation of emotional and affective functioning. This influences behaviour." He says, for example, that with young adults, rational decision-making may not always be exercised effectively under stressful or emotionally charged circumstances.

"This is about making the young adult court like the youth court – less adversarial, a wider range of professionals engaged in

the court, a problem-solving approach that seeks to tackle underlying problems – and delays sentencing until these have been worked on.

"I am in support of a specialist response to neurodisability because of the challenges that disability poses both to access to justice and to intervening to address offending," Nathan says.

Nathan, who is a Professorial Fellow at The University of Sheffield, was in New Zealand at the invitation of the University of Otago as its William Evans Fellow. He was hosted by the Donald Beasley Institute.



# Ben takes a boot-camp challenge



Ben Johnston with his Horizons team friends on his Outward Bound adventure.

Ben Johnston wanted to start 2019 with an adventure and decided to do an Outward Bound New Zealand course at Anakiwa in Queen Charlotte Sound. For this he knew he needed to be fit.

Ben, 24, from Oamaru, was already a keen Special Olympics swimmer, and he added more walking and running and Zumba to his schedule. He also started an eating plan that included plenty of salads, kebabs and chicken wraps.

He got fitter, lost four kilos and was ready for action. What he wasn't ready for was having to hand over his iPad and iPod at Picton. Eight days straight with no devices was where the boot camp really started, and it was very tempting at first to try to hide his devices in his suitcase. Ben spends a lot of the day – “and half the night”, says Mum Pip O'Connell – listening to music or playing games.

But it only got tougher. Mornings for Ben usually start about 8am with a wake-up from his Mum or someone else.

At Anakiwa the day starts before 6am with a swim.

And it got tougher still. Ben says the hardest day was rock climbing. This meant a long hike in the heat to where they were going to climb and then a hike back home again – and hanging off a rock wall in between.

Ben was one of 12 who did the Outward Bound Horizons course in February for young adults with intellectual disabilities. He was proud of being able to meet the challenges, including flying Timaru-Wellington-Blenheim and back on his own and sleeping out overnight with only a tent, torch, sleeping bag and pillow.

At the end of his adventure Ben arrived back at Timaru Airport to find that his flatmates, who had been missing him, had driven from Oamaru to meet him.

Every day Ben recorded his adventures in his journal along with the names of the friends he met, and he is keeping in touch with them.

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