

# Community MOVES

SARYN WANTS TO PLAY – Page 3

BIG YEAR AHEAD FOR  
ACCESSIBLE PROPERTIES – Page 4

GENE RESEARCHERS SEEK CAUSES  
OF RARE DISORDERS – Page 6

ARTS FUNDING UNLOCKS CREATIVITY – Page 8

March 2017

**ihc**  
IN YOUR COMMUNITY

# Personally Speaking

Happy New Year to you all.

We start another year determined to tackle new projects and continue our core work with an unwavering commitment to the people we support. Each year the need for the money we raise increases. But our service contracts remain tight, so we must continue to raise extra to make sure people can have satisfying lives in the community.



Fundraising is an increasingly competitive business. More and more people in New Zealand are in need and we continue to fight to ensure people with intellectual disabilities have good lives.

We work hard for every dollar we raise. We raised good money through the Calf and Rural Scheme this season, despite pressure on dairy farmers, and our Smile Club has a record number of regular donors. But our appeals remain just as important as ever. This year our Annual Appeal features seven-year-old Saryn and her family, and you can read more about them on page 3. It is with great pride that we can help the family by providing information and extra support now – and we will be there in the years to come.

I want to personally thank everyone who donates to IHC. Your donations mean we can advocate for people with intellectual disabilities at community, national and international levels. The number of success stories coming out of our volunteer programme is impressive and our Associations continue to make a difference in local communities – thanks to them and to you. Our library has had a stellar year introducing e-books and taking over the Barnardos library collection, ensuring valuable resources are now accessible to everyone. In fact, last year our library issued more than 4600 items, sent out 492 free books to families to keep and registered nearly 1000 new patrons – these are all record-breaking numbers. We know that without these great programmes and services families and individuals can feel isolated. If you know someone who might like to support our work or would like some support themselves, please encourage them to get in touch.

This year will see some change in our services as we roll out new technology that will provide immediate information and new tools to help staff do their jobs. This technology will also mean people working all over the country can feel more connected and will have greater access to online learning materials.

I am pleased to draw your attention to another change in our organisation – Greg Orchard has taken up the newly created role of Chief Executive of Accessible Properties. You can read more about this on page 4.

Finally, IHC was delighted to be in a position eight years ago to endow the IHC Foundation. We are pleased to be able to showcase just a small sample of the initiatives the Foundation has funded. I am particularly delighted with the diverse activities and organisations that have been supported.

Ralph Jones  
Chief Executive

# Saryn wants to play – let’s help



Saryn with her younger brother Axel and mum Kerry. Saryn’s brothers take time out to help her.

Saryn Semmens’ brothers couldn’t understand why the kids in the pool didn’t want to play with her when the family recently went on holiday to Hanmer Springs.

Saryn, 7, has Koolen de Vries syndrome, a very rare genetic condition that can cause multiple disorders – and misunderstandings.

“Saryn cleared the pool every time she went in as the other kids moved out of the pool and away from her. I found myself constantly explaining to other parents that she is OK to play with their kids,” says Kerry, her mum.

Kerry says one of the most difficult things about Saryn’s disability is how other people react to her.

“It affects the boys too when no one will play with them as they are with her. I was really upset and angry for a couple of days after we got back.

“She’s just a little girl who wants to have fun, like all the other kids,” Kerry says.

Kerry and Steve Semmens live in Tapawera, a small rural community about an hour south-west of Nelson. They run a 400-hectare dairy farm

and raise their three children, Kade, 9, Saryn and Axel, 4. Saryn and her family feature in this year’s IHC Annual Appeal, which runs throughout February.

When Saryn was born with a fused skull, surgeons inserted a plate in her head to make room for her brain to grow. But Kerry suspected something else was wrong. At 13 months, following a seizure, tests revealed she had Koolen de Vries syndrome.

“Saryn’s diagnosis turned our lives upside down. We went through grief and anguish and it took us a couple of years to accept she had it,” says Kerry.

“We didn’t know what to expect, or what the future would hold for Saryn. “We were desperate for information and went to the local library, but they didn’t have any information about Koolen de Vries. Then I found out about the IHC library and that has turned out to be a fantastic resource for us. They sent us a pack of information that explained the things Saryn would struggle with and how we could help her.

“Now, any time I need more information I request books online and they arrive within a couple of days.”

## CONTENTS

- 2 Personally Speaking
- 3 Saryn wants to play – let’s help
- 4 Big year ahead for Accessible Properties
- 6 Gene researchers seek causes of rare disorders
- 8 Arts funding unlocks creativity
- 10 Open studio brings museum to life
- 11 Ivan puts a smile on the radio dial
- 12 Board Member profiles
- 14 Sailability sets sights on new jetty
- 15 Clowning around with circus skills

**CHECK US  
OUT ON  
FACEBOOK**



**KEEP UP WITH WHAT IHC IS DOING – FOLLOW OUR CAMPAIGNS AND BE THE FIRST TO READ OUR STORIES AND SEE OUR VIDEOS.**

**WE’LL KEEP YOU POSTED WITH NEWS, VIEWS AND BOOK REVIEWS FROM THE IHC LIBRARY.**

**WE’D LOVE TO HEAR FROM YOU.**

**SO JOIN THE CONVERSATION.  
FACEBOOK.COM/IHCNEWZEALAND**

**COVER IMAGE:**  
Young Tapawera girl Saryn Semmens is the face of this year’s Annual Appeal. See story at left.

# Big year ahead for Accessible Properties



Hamilton's Peachgrove Road tenants (from left): Alison Severinsen, Barry Ross and Alan Clarke are enjoying a revamp of their communal outdoor area. Accessible Properties transformed a grass lawn at the former council-owned pensioner housing with gardens, picnic tables and a barbecue. – PHOTOGRAPH: CHRISTEL YARDLEY/FAIRFAX NZ

IHC's property company is perhaps entering its most significant year yet. It is about to take on more than 1000 homes in Tauranga, previously managed by Housing New Zealand.

As well, more building projects are under way. Progress is being made on a contract to provide more than 350 social housing places in Auckland and improvements are being made at some of the sites in Hamilton, where more than 340 homes were acquired last year from Hamilton City Council.

To do all this, Accessible Properties has a new Chief Executive determined to match the focus on new business with bringing benefits to the IHC portfolio and its tenants.

Greg Orchard started his new role

in January and joins the staff at Accessible Properties with a strong knowledge of the organisation, having served on its board. Greg also has considerable experience in the housing sector, having held the roles of Chief Financial Officer and General Manager of Asset Services for Housing New Zealand (overseeing the management of 67,000 properties) and most recently as Chief Operating Officer at Wellington City Council (with responsibilities including a portfolio of 2500 homes). The Chief Executive role is a newly created position that recognises the change in scale of the organisation.

"I'm delighted that Greg has agreed to lead the organisation heading into a new phase," says IHC Group Chief Executive and Accessible Properties Board Member Ralph Jones. "He has great experience but also a

determination to prioritise and improve IHC's homes alongside developing new business."

"Tauranga provides us with a fantastic opportunity," says Greg. "Business-wise it almost doubles the number of homes Accessible Properties manages. We are committed to improving homes and services for those tenants, and it makes sense financially and in terms of business sustainability and diversity for both Accessible Properties and IHC.

"But it also builds scale and expertise on the ground for us – we need more staff, we need to find new ways of working and we need to be even more flexible about the services we provide.

"All this is great news for the IHC homes and IDEA Services, and for the independent tenants who live in them."

Greg says the business has been growing quickly and it's time for a renewed focus on the IHC properties, which still make up nearly half of the number of homes.

"I want to know what IDEA Services and tenants with intellectual disabilities and their families need right now and in the future. Do we have the right houses in the right places? Are they the right size? Are we getting the balance between integrated, independent community living and practicalities for staffing right? Do we need to be more embracing of technology? What will we learn from Tauranga in the next year that will help provide the best possible service to IHC, IDEA Services and tenants?"

Greg says there will be changes within the team too. "We already have great people but we'll need more and a new management structure to make this work."

It's clear that Greg gets a lot of satisfaction out of the housing business. "There is so much pressure on housing at the moment – prices are still climbing at alarming rates, supply isn't keeping up with demand and more and



Barry Ross and Alison Severinsen in the new patio area at Peachgrove Road. Barry supplied the umbrellas. – PHOTOGRAPH: CHRISTEL YARDLEY/FAIRFAX NZ

more people are finding themselves in need of help to get into a home.

"We all want a home that is warm, safe, suits us and is a nice place to be," he says. "Whether we are providing homes for people with

disabilities, older people or those on low incomes, I am determined that Accessible Properties is going to lead the way in providing top-quality homes and services that make a difference to each and every tenant."

*...continued from page 3*

Saryn has a developmental delay and intellectual disability, and she experiences regular seizures. She can only say a couple of words and is not yet toilet trained. Saryn has also recently begun to show signs of anxiety.

Despite this, Kerry says Saryn is making good progress with the help of her two brothers. "The boys play with her a lot and, without knowing it, teach her things. They've been helping her to get her shoes on and off and now she can do it for herself. She watches what they do and copies them."

Kade, Axel and Saryn are all learning to communicate with signs and, in the past six months, Saryn has started to play with kids at her school and interact more with others.

The family's challenges come from things that many people take for granted. Finding good people who can help care for Saryn is one of those challenges. "There are so many things you have to learn about caring for children like Saryn and how their brains work."

The family feel supported in the small community they live in. Saryn attends the local primary school full time and the kids there are happy to include her. She

catches the bus and some of the older kids sit with her on the ride to and from school. They have been taught what to do if she has a seizure, and they sing songs and keep her entertained.

Kerry doesn't know what the future will hold for Saryn, but she and Steve want to give her as many opportunities as they can. They want to make sure she has the chance to work and to live independently if that's what she wants to do.

"When we look to the future I know we'll need even more help from IHC. We will need more information and advice on caring for Saryn to make sure she reaches her full potential."

# Gene researchers seek causes of rare disorders

Families may be closer to discovering the genetic causes of intellectual disabilities affecting their children thanks to a University of Auckland research project being funded by the IHC Foundation.

A research team, led by Professor Russell Snell, Dr Jessie Jacobsen and Associate Professor Klaus Lehnert, of the School of Biological Sciences, is using the latest genome sequencing technology to look

for a genetic diagnosis for children with undiagnosed, rare neurodevelopment disorders.

Twenty families from throughout New Zealand are participating in the two-year pilot study to discover the genes responsible for disorders that can't be explained through standard tests. The IHC Foundation is meeting the \$147,000 cost of collecting and reading the DNA.

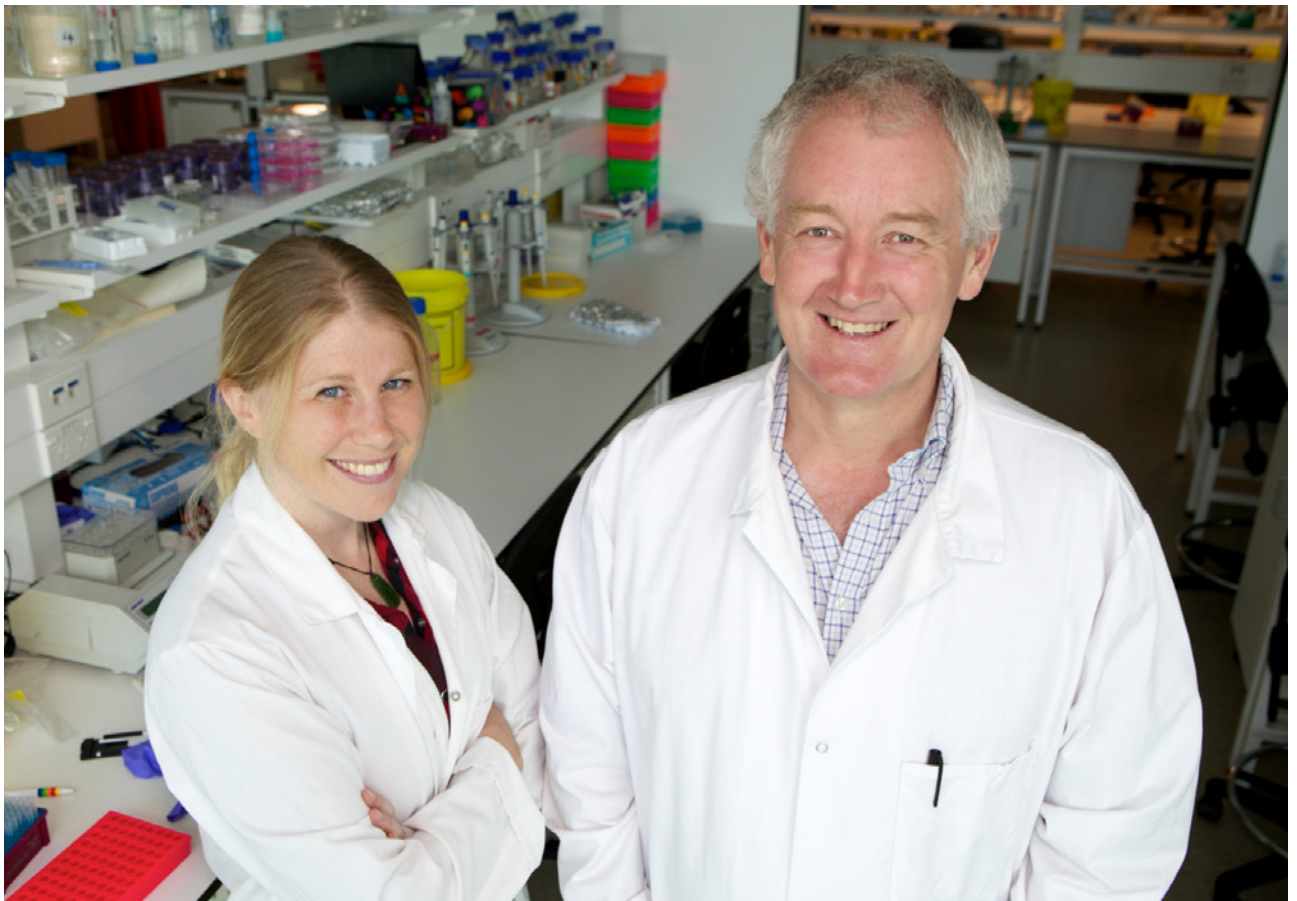
"Sequencing is reading the DNA that is in all of our cells," Russell says. "The great advantage of the new method is that you are reading all the pieces of DNA

in one step. The magic is taking all of these small pieces and comparing them to a standard."

A genome is the complete set of genetic instructions or genes contained in each cell. In humans, each genome contains all of the information needed to allow us to grow and develop.

"We get the DNA from either blood samples or saliva samples. We collect DNA from the parents, where available, along with the affected individuals," he says.

The participants with intellectual disabilities are mainly children.



Researchers Dr Jessie Jacobsen and Professor Russell Snell are using the latest genome sequencing technology to look for diagnoses for children with undiagnosed, rare neurodevelopment disorders. – PHOTOGRAPH: NEUROLOGICAL FOUNDATION OF NEW ZEALAND

Only the individuals will have Whole Genome Screening, which looks at the complete set of DNA at a single time. “In the parents we sequence all the exome – the protein-coding regions. It’s approximately half the cost of sequencing the genome,” Russell says.

The exome in humans is about 1 percent of the total genome, but is thought to harbour about 85 percent of DNA variations that cause disease.

“The rationale behind that is that we expect to see variations in affected individuals. Some of the variations might be in the protein coding, but some of them might exist elsewhere.

*“The majority of conditions are rare and cannot be identified through this slow and expensive approach. This leaves the patients and their families without a way to assess the risk of future pregnancies and can lead them on lengthy and costly diagnostic odysseys.”*

“If we had more money we would sequence the whole genome in all individuals, but this group of cases will tell us how successful this more limited approach is,” he says. “For the current work the funding has come from the IHC Foundation, which is extremely generous. We are always looking for more funding as we have vastly more requests than we can support.”

The direct cost of sequencing is now as low as an overnight stay in hospital, but it’s not yet part of a routine approach to treatment. Russell says the aim is to build a case for making genome screening part of routine clinical practice for undiagnosed conditions and conditions likely to be inherited.

“Traditional gene-screening approaches, where you only select one gene at a time for analysis, are appropriate only for well-known conditions.

“The majority of conditions are rare and cannot be identified through this slow and expensive process. This leaves the patients and their families without a way to assess the risk of future pregnancies and can lead them on lengthy and costly diagnostic odysseys,” he says.

“Fundamentally, understanding the genetic basis of a condition is a very important first step towards the identification or development of a treatment.”

He says that a diagnosis can often help focus treatments.

Being able to put a name to a condition and to be able to describe causation can give families comfort and remove the worry that some environmental factor has caused a condition.

“Some families are interested in having more children, and finding a cause can mean they can make choices about having more children.

“We are working hand in hand with clinical geneticists across the country and we are building the evidence for the routine application of these technologies. Our hope is that

as soon as a child presents with a developmental condition, the first port of call is that they will have their DNA sequenced if they choose.

“All the variations that we discover in our research lab are re-checked by the formal diagnostics laboratory and the results, if the patient or parents would like them back, are delivered through the formal genetics service,” Russell says.

The team believes that the new, cost-efficient genome-wide sequencing can dramatically increase the rate of genetic diagnoses in rare conditions.

In the course of this research project, the team is expecting to find the gene mutations responsible for neuro-developmental disorders in more than 10 of the 20 participating families. Russell says they can make that prediction based on past experience.

“There are some conditions where intervening early with a therapy can prevent longer-term damage.” Already the team has been able to identify two cases where early intervention has proved to be beneficial. “If the conditions were recognised from birth, the benefit of treatment could have been even greater,” he says.

“As a group we are quite good at identifying causal DNA variants now, and at least as efficient as the best groups in the world. This is because we are a research group. We spend more time on each case than a diagnostic laboratory can currently. However, with the experience being gained through our work and internationally, the process is becoming increasingly efficient.”

# IHC Foundation arts funding

The forces of art, music and dance are empowering new participants among people with disabilities, and the IHC Foundation is making an important contribution to that change.



Jolt dancers Michael Krammer and Josie Noble show their moves in the Move tutor training and community dance programme.

Since 2010 the IHC Foundation has distributed \$550,000 to community-based and mainstream arts organisations working with people with disabilities. The money has funded disabled people not just to watch, but to create and participate in an arts sector that has often been reserved for others.

The IHC Foundation recognises that people with disabilities can struggle to express themselves and sees the creative arts as another way for people to communicate. It allows them to participate in the social and cultural life of their communities, and it also lets mainstream audiences appreciate the previously untapped talent of people with disabilities. For six years the Foundation sponsored the Attitude Artistic Achievement Award, but most of its focus is on funding those working with artists and performers.

Chamber Music New Zealand's accessible concert series has been funded by the IHC Foundation

since 2012. Last year, the series won the Arts Access Creative New Zealand Arts for All Award for its "ground-breaking" relaxed performances and workshops.

The series is led by Wellington-based community musician Julian Raphael, who teams up with musicians to deliver the concerts throughout the country. "What can we do that's the easiest thing for us to all feel connected? Make some music together. So simple," he says in the video, *Connecting Through Music*, produced by Arts Access Aotearoa about the concerts.

For the past four years the Christchurch integrated dance group Jolt Dance has received IHC Foundation funding towards its Move tutor training and community dance programme. "Move is New Zealand's only dance teacher training scheme for people with disabilities," says Jolt Dance Artistic Director Lyn Cotton. "It has only been possible with the ongoing help of the IHC Foundation, who have supported

our vision at Jolt to embed a disabled perspective into all our work and create genuine pathways for leadership for our dancers. Our trainees have skills we don't possess. The ability to call yourself a dancer and a teacher is empowering and challenges beliefs around the potential of people with disabilities and the beauty of diversity."

In a further development, the Foundation last year funded a collaboration between Jolt and Christchurch Symphony Orchestra (CSO) musicians to take the multi-sensory show *Fish* on tour to Wellington and Auckland. *Fish*, is designed especially for people with profound disabilities. The CSO says the aim was for a disabled person to be able to experience theatre, dance and music with the same immediacy and power as a person without a disability.

Michelle Walsh, CSO Marketing Manager, says people had the



# unlocks creativity

opportunity to put their hands on a drum and know what it felt like to touch. “Live music can be spontaneous – it just happens through the nature of it. Our players are able to react and know what’s going to work and what isn’t going to work. Our musicians are very keen to share their love of music.”

Consistent funding over six years has helped the Auckland InterACT Disability Arts Festival to double in size. The festival was first held in 2011 with 2000 people attending, and by 2016 around 450 people were performing or exhibiting to more than 4000 people at the Corban Estate Arts Centre. Last year festival-goers had a choice of 26 different performances – a new act on the main stage every 20 minutes – for the three days of the festival. On offer were seven drop-in art activities and workshops in drumming, dance, clowning and hip-hop group singing.

The driving force of those behind the festival is the inclusion of people with disabilities, particularly those with significant impairments. The festival is seen as a regular part of the year for disability service providers and special educators, says Festival Director Paula Crimmens – 90 percent of those attending have disabilities.

Paula says funding from the IHC Foundation has enabled some good planning and preparation from year to year. “It gives us freedom and it gives us flexibility,” she says. “As time has gone on we have seen the things that work and we have changed the format.”

The event is now held from Wednesday to Friday, rather than over a weekend, to make it easier for special schools and disability providers to attend. “That has been a major change,” she says. “I think we have been able to create an atmosphere of



*Wake Up Tomorrow* won the Best of Fringe Award in the 2015 New Zealand Fringe Festival. Front row (from left): Axel Evans and Jacob Dombroski. Second row (from left): David Cree and Michael Hebenton. Third row (from left): Catherine McBride and Kwame Williams-Accra. Back row: Janiece Pollock.

inclusiveness. We want there to be something that people who are profoundly disabled can come to and participate. We want people to have ownership.”

A new open arts studio at Te Manawa Museum of Art, Science and History in Palmerston North (see story, page 10) has been established with support from the IHC Foundation in response to community demand. This grew out of a four-year partnership between the museum and the disability art space Creative Journeys and a groundbreaking ‘Inspired By’ exhibition, in which works by artists with disabilities were hung alongside high-value works in the museum’s collection by such artists as Colin McCahon, Buck Nin and John Bevan Ford. Feedback from artists and visitors led to the opening of NOA, a facilitated open studio that is accessible and supportive of people with disabilities.

Māpura Studios in Auckland was first funded by the Foundation (as the Spark Centre of Creative Development) in 2010 for a powerful project ‘Portrait Speaks’. The project consisted of a six-month pilot programme in portraiture and personal narration for 12 artists of all

abilities. This was followed by a public exhibition and seminar presented by the participants about their work and their experiences of working in an inclusive environment. The organisation was funded again in 2015 and 2016 to support its visual art programme and to fund community exhibitions.

Māpura Studios’ Community Development Manager Jenny Hutchings says its inclusive studio encourages a sense of belonging and social connection in a creative community. “IHC Foundation funding helps us provide quality creative art and art therapy programmes, and to professionally present exhibitions in public and community galleries so the diversity and unique ability of the artists can be celebrated. For many non-verbal artists, their art is their voice.”

When it comes to theatre, it was the opportunity to see young people learn the craft of acting that convinced the Foundation to fund two shows staged by the Everybody Cool Lives Here Trust, co-founded by two Wellington-based theatre practitioners, Nic Lane and Rose Kirkup. The first show, *Wake Up Tomorrow*,  
...continues on page 13

# Open studio brings museum to life

A group of artists has taken up residence in the foyer of Te Manawa museum in Palmerston North to share their creativity with each other and with visitors and tourists alike.

They are part of NOA Open Studio, which opened towards the end of 2016 with funding from the IHC Foundation. It is one way in which the museum, art gallery and science centre is bringing the life of the community inside the building.

Chief Executive Andy Lowe says Te Manawa has a concept called 'museum without boundaries'. "It's about mixing it up and breaking down the barriers. We want to bring people who are often invisible and make them visible in our environment," he says.

He says the IHC Foundation funding had "put wings on an idea" by enabling Te Manawa to really explore what it means to be inclusive.

NOA Arts Facilitator Aroha Lowe, his wife, has had a long involvement with outsider artists, with artists who have disabilities, with the elderly and with children. She says NOA is about sharing and inhabiting public space to create art together.

"The right of citizenship means that we can move through public spaces. We are part of things that go on. Te Manawa is funded by the ratepayer and anyone can come here, but some people have been under-represented," she says.

"I was raised by my father who was disabled. He was seriously injured in a traffic accident when I was three – hit by a vehicle when he was walking across a crossing in Auckland. My mother had died of cancer just months before this. So, my father, post-coma, had to



Artist and DJ Anaru Davis is a regular at NOA Open Studio.

learn to talk and walk again.

"He was my hero, in that everyday, just-my-Dad kind of way, and I learned a great deal from him about bravery as he struggled through what was largely difficult terrain for a disabled father. We used to visit galleries, museums, shops etc before there were wheelchairs and other supports available," she says.

"He would love Te Manawa. There are chairs just inside the door – wheelchairs available. The floor is level, the spaces accessible; the toilets too, of course. Staff are friendly and welcoming of those of us with disabilities."

Aroha says NOA stands for Notes Of Art. Noa is also a Māori word that can mean open, safe or free from restriction. "In Te Ao Māori, through powhiri, karanga,

karakia and whaikorero, we use ritual to establish safety, to allow for each other's difference and to find common ground," she says.

The sessions are mixed ability and for all ages. "It's about whoever is here on the day. People come in with clear ideas and it might be a very solitary experience. Other people come in and see who's here and it might be a very organic thing," she

says. Also welcome are tourists, kids with their grandmas or caregivers, known and emerging artists, and visitors waiting for exhibition queues to clear.



All-comers are welcome at NOA Open Studio, which operates from the foyer of Te Manawa museum in Palmerston North.

# Ivan puts a smile on the radio dial

Ivan Dingle used to be a man who shut people out. Now he puts a smile on the radio dial through his Radio Kidnappers show.

Taradale man Ivan has a genetic disorder called Prader-Willi syndrome, which, among other things, causes a compulsion to eat. He used to live alone with a support person and liked to keep to himself.

But his sister Rachael Engelbrecht says Ivan's life changed for the better when he decided to set some goals for his life. It started with a job delivering the *Hawke's Bay Today* newspaper, travel to Perth and then, for the past three years, a slot on access radio in Hastings. In 2015 he moved into an IHC group home with flatmates.

Rachael says when Ivan's support staff at IHC talked to him about personal goals he said he wanted to go and see his family in Perth, but he first had to save the money – "getting this job with the paper delivery, it became a reality for him. He actually flew to Perth twice and to Christchurch".

His first show on Radio Kidnappers featured music and fun facts. He called the show *Ivan Dingle's Jingles*.

Programme Administrator Ken Morrison says that to begin with, Ivan was quite shy. "But, being a good reader, Ivan was able to follow the prepared script and, little by little, his delivery improved to the extent that he actually started enjoying what he was doing."

In his next radio series, Ivan included interviews with local people. The first person he chose was journalist John Ireland. Ivan used to pick up his newspapers from the old *Hawke's Bay Today* office in Tennyson Street, and



Ivan Dingle records his show at the Radio Kidnappers studio in Hastings.

often John would stop and have a chat with Ivan about his job. Ivan decided to turn the tables and talk to John about his job.

Next up was an interview with SPCA Manager Bruce Willis – together with background contributions from various animals. Margaret Baker, a volunteer helping to organise the local Special Olympics contingent, was interviewed, together with swimmer Karen Martin and golfer Josh Fergusson. Ivan ended the series by questioning local MP Stuart Nash about after-school care for vulnerable children and the closure of a swimming pool that had been used therapeutically by disabled people.

"It was hard work. I couldn't really say some words properly," Ivan says. "I did a lot of radio programmes and interviewing people, and a lot of places to go and a lot of interesting people."

Last year, Ivan launched his third series of programmes, *Ivan Dingle's Mix & Mingle*, this time visiting some Hawke's Bay attractions, including the Faraday Centre museum of technology, Trainworld and the Hawke's Bay Holt Planetarium in Napier, the Gypsy Rose Tea Museum in Taradale and the Hawke's Bay Farmyard Zoo in Haumoana. He interviewed those in charge and recommended the attractions to his listeners.

"We've noticed a huge change in Ivan over the years," says Chris Gane, Technical Administrator at Radio Kidnappers. "When he first started coming to the Radio Kidnappers recording studio in Hastings, Ivan wouldn't look us in the eye, but he certainly does now, as he has loads more confidence, and you can actually hear the smile in his voice on air." Ivan received a Radio Kidnappers Broadcasting Achievement Award at the end of 2016.

# Meet the IHC Board

At IHC we are privileged to have a Board combining people with professional backgrounds and family members with lived experiences of intellectual disability. All our Board Members are champions of the IHC Mission.



The IHC Board (from left): Neil Taylor, Barbara Rocco, Rob Steele, Donald Thompson (Chair), Shelley Payne, Ralph Jones (CEO), Michael Quigg and Anne Gilbert.

We have eight Board Members, including our Chief Executive, who is a voting member:



## Chair Donald Thompson

Donald is a parent and has been involved with IHC for many years in various governance roles. He is a director of IHC's subsidiary companies IDEA Services and Accessible Properties and an IHC-appointed Trustee to the IHC Foundation. Donald is a retired Oamaru farmer who resides and has business interests in Wanaka. He is the former IHC President and a former Trustee of the Donald Beasley Institute.



## Chief Executive Ralph Jones

Ralph is IHC's Group Chief Executive. He is a director of IHC's subsidiary companies IDEA Services and Accessible Properties and an IHC-appointed Trustee to the IHC Foundation. He is a chartered accountant and Fellow of Chartered Accountants Australia and New Zealand. Ralph has held many roles in the disability sector, including as a Trustee of the Donald Beasley Institute and Treasurer and Secretary General of Inclusion International. He has been honoured with Life Membership of Inclusion International and is currently a director of Workability International. Ralph's career has included finance and accounting roles in the commercial and public sectors, including with Ernst & Young.



**Barbara Rocco**

Barbara is a parent and has been involved with IHC for many years. She has formerly held the roles of Vice-President and President, and is the current Chair of our Member Council. Barbara was previously a high school teacher and is the former owner of a vineyard and restaurant business in Blenheim. Barbara is an IHC New Zealand Life Member.



**Anne Gilbert**

Anne is a parent and has been involved with IHC for many years. Anne is the current Chair of the IHC Wellington Association and is the Public Sector Project Manager at Transparency International New Zealand. She is also a founding Trustee of the Fuse Charitable Trust.



**Shelley Payne**

Shelley is a parent and has been involved with IHC for many years. She is a previous Vice-President of IHC. Shelley is currently an owner and director of Trinity Wharf Hotel in Tauranga. She is a director of IDEA Services and is the Chairperson and Trustee of a community-based vocational service in Tauranga.



**Rob Steele**

Rob is the Chief Executive of BakerAg, a Trustee of the Wairarapa Creative Arts Festival Trust and has formerly held the roles of Secretary General, International Organization for Standardization (ISO), Chief Executive of Standards New Zealand and Chief Executive of Electra.



**Neil Taylor**

Neil serves on both the IHC and Accessible Properties Boards and is the Chair of the IHC Audit and Risk Committee. He has been involved with IHC for many years, including as a Vice President and as President of the South Taranaki Association. He is a chartered accountant and Fellow of Chartered Accountants Australia and New Zealand. Neil has held a number of other governance roles and is an IHC New Zealand Life Member.



**Michael Quigg**

Michael is a partner who heads the Employment Team at Quigg Partners in Wellington, specialising in all areas of employment law and workplace health and safety. He is also a member of the Institute of Directors and a presenter for the Institute.

was a collaboration with Active, an IDEA Services group for young people in Wellington with intellectual disabilities.

Rose says *Wake Up Tomorrow* was a community show and its focus was on mentorship. But for the second show, *No Post on Sunday*, the young people were given the opportunity to audition and be paid as actors.

She says three young men from the first show successfully auditioned and went to work full time for six weeks. "It was a huge development," she says. "This was about creating more professional development opportunities for the guys." And Rose says this was a vision also shared by the IHC Foundation.

*Wake Up Tomorrow* was part of the 2015 Circa Theatre programme during the New Zealand Fringe Festival, winning six awards, including Best of Fringe.

Young people with disabilities were again key participants when it came to research by Te Koki New Zealand School of Music. The Foundation funded three action research projects, which involved the young people as researchers alongside Dr Daphne Rickson (Victoria University of Wellington). Daphne says her research is about extracting information from the young people themselves – ensuring they have a voice.

"I love seeing people grow through the music and through the research," she says. As therapists, they are looking at how music-making can benefit the young people in various ways – "social, emotional and communication are the main ones – and the process of music-making, being able to participate, rather than the musical output, is the most important thing".

IHC Foundation Chair Sir Roderick Deane and his wife Lady Gillian have been passionate lifelong supporters of the arts and young artists. "I am particularly delighted that we are able to make such a substantial contribution to bringing the thrill of live performance and the experience of creating visual art to people who might otherwise be excluded," says Sir Roderick.



Duncan Renouf sailed for four years on Wellington and Porirua harbours. His first solo sail was in August last year. Duncan died in January this year and his funeral service, led by Don Manning, celebrated his love of sailing.

## Sailability sets sights on new jetty

When the north-westerly winds are blowing, the sailors from Sailability Wellington head for the shelter of Porirua harbour. No one wants to miss a day's sailing.

Sailability Wellington, an organisation that makes it possible for people with disabilities to sail, now operates from three bases in Wellington – Seaview Marina, Evans Bay Yacht & Motor Boat Club and, for the past year, from the float plane jetty on Porirua harbour.

The organisation's 62 volunteers support more than 200 sailors, but there are more than 80 on the waiting list. To meet demand, particularly in the Porirua-Kapiti region, Club Captain Don Manning is working hard to boost its capacity even further. He is fundraising to build a new jetty at Porirua, next to the Titahi Bay Boating Club, because the existing jetty can be used only at high tide. A new jetty will cost \$150,000 and give them access to deeper water and longer sailing hours – and a calmer sailing

option when the winds are too high for comfort on Wellington harbour. The jetty will also be available to local sailors.

“We would love to see it in for February next year because there is a Sea Scout jamboree being held on Porirua harbour.”

Don says that for the past 15 years his organisation has made it possible for sailors with disabilities to leave their limitations on shore. Once they get on board the emphasis is on what they can do – helping a yacht solo or taking part in a regatta. In an average year, each participant will get around 30 days of sailing. A number of sailors who volunteer with Sailability Wellington also have disabilities.

“Some people are scared of the water and we help them overcome it,” he says.

“When they sail solo for the first time, we have their parents and caregivers on the wharf and generally they cry. The mothers and grandmothers and fathers, who have all got tears in their eyes, are looking at us saying, ‘I am

amazed that you would trust our son or daughter or granddaughter with an expensive boat.’”

The yachts are all modified for extra stability, with lead in the keel, but it makes them much heavier to handle than other yachts. In 2015 the IHC Foundation contributed \$25,000 to purchase a sea crane and sling, buy a container to store boats, and cover engineering and other costs associated with the jetty project. In 2016 the Foundation granted another \$25,000 to increase the number of volunteers and Club Captain hours.

Don says the Sailability Wellington Trust is bigger than the average yacht club. It owns 23 modified yachts, two safety boats, three shipping containers for storage, VHF radios and 100 life jackets – all funded by subscriptions, donations and fundraising.

IHC Foundation Chair Sir Roderick Deane says the Foundation is delighted to support the excellent work done by Sailability to enable people with intellectual disabilities to experience and enjoy sailing.



The juggler disguised in the top hat and sunglasses is Bradley Cossar from Wellington youth service Active.

## Clowning around with circus skills

The room was full and the crowd was expecting to see some thrills – maybe even some spills – at the IHC Circus Showcase in Wellington.

There were tight-wire walkers, hula hoop hip swingers, trapeze artists, jugglers and clowns. And if anyone needed to land heavily, there were crash mats. Nobody did.

Bradley Cossar was juggling in a top hat. Zak Laing was doing “a star” balancing on aerial silk and supported by Circus Hub trainers Richard Martin and Katie Roberts. Sharleen Monaghan was taking a break from her favourite hula hoops on a crash mat.

They were among eight circus performers from three IDEA Services Wellington day bases – Alpha, Aranui and Active – who showcased their skills at the Circus Showcase at the Circus Hub in Newtown, Wellington in early December.



Zak Laing balances on ‘aerial silk’ supported by trainers Richard Martin and Katie Roberts.

They had been preparing for it all year. In February last year, IHC received a grant of \$4470 through Wellington City Council and Creative New Zealand for two circus performing skills workshops for people with intellectual disabilities.

The first eight-week course attracted around 20 participants. They came to try out and see if they wanted to train for a performance. Eight people continued to a second performance workshop.

Organiser Rohana Weaver, from IDEA Services, says circus skills provide many benefits. Participants have increased confidence in themselves and what they can achieve. “Physically, circus increases body awareness and balance skills, and the physical exercise is beneficial.”

Circus Hub trainer Mary Weir, who helped lead the workshops, says there is something in circus for everyone. “If you get the right programme, circus will tailor to almost anyone and it certainly encourages acceptance and inclusion.” She says one of the beautiful things about circus is its social side – “the real sense of cooperation and achieving something together”.



Sharleen Monaghan in Christmas costume takes a break on a crash mat.

**IHC NEW ZEALAND  
INCORPORATED**  
ihc.org.nz

### IHC BOARD

Donald Thompson, Chair  
Anne Gilbert  
Ralph Jones, Chief Executive  
Shelley Payne  
Michael Quigg  
Barbara Rocco ONZM  
Rob Steele  
Neil Taylor

### IHC MEMBER COUNCIL

Barbara Rocco, Chair  
Andy Crawford  
Janet Derbyshire  
Scott Miller  
Pip O’Connell  
Kay Pearce  
Sylvia Robertson  
Danny Tauroa

### PATRONS

Sir Roderick & Gillian, Lady Deane

### NZ LIFE MEMBERS

Dr Donald Beasley CBE  
Dr Terry Caseley  
Sir Roderick Deane KNZM  
Jan Dowland  
John Hanning  
John Holdsworth ONZM  
Sir Colin Meads KNZM MBE  
DCNZM  
JB Munro QSO  
Lynne Renouf  
Barbara Rocco ONZM  
Tony Shaw  
Neil Taylor  
Charlie Waigh  
Maureen Wood

### 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

### COPYRIGHT

*Community Moves* is published by IHC New Zealand Incorporated. The content of *Community Moves* is copyright. No part of this publication may be reproduced or transmitted in any form or by any means without the prior written permission of the publisher.  
ISSN 1171-8587

