

# Community MOVES

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## Personally Speaking

In February every year IHC holds its Annual Appeal asking Kiwis to donate money so that we can continue our work for families.



Government funding does not cover all the work we do, and we need help to fill those gaps. One of these gaps is autism. There are long waiting lists for our autism support programmes. Government-funded programmes (ASD Plus, ASD Communication & Behaviour Service, Growing up with Autism) are at capacity and some families are waiting more than a year for access to these services.

As a consequence of the long waiting times for families, IHC has been running free workshops to provide help sooner. Since April 2015, 53 workshops have been held across the country in 12 North Island centres and four South Island locations. They cover essential information about ASD and practical ASD support strategies. Last year nearly 500 families signed up.

This year we are introducing a new series of two-hour workshops for autism support targeting pressure points, such as managing anxiety, sensory processing and successful play.

Our Annual Appeal for 2016 focuses on autism support and features the Galvan family from Hamilton. Ch'von and Dave care for two daughters, Olivia and Bonnie, who both have autism. You can read their story on page 4 and watch the video at [ihc.org.nz](http://ihc.org.nz) and on Facebook at [facebook.com/IHC.New.Zealand](https://facebook.com/IHC.New.Zealand)

As Ch'von says, some families give up looking for help when things get too hard. IHC has been here for more than 65 years supporting people with intellectual disabilities and their families, but we can't do it alone.

Donations to IHC make an enormous difference – 35,000 people in New Zealand have intellectual disabilities. The money raised through the Annual Appeal is spent on IHC services not funded by the Government, including:

- Community information sessions to let families know what support they are entitled to and how to access it
- Advocacy on behalf of people struggling to get a fair deal
- IHC's library – the largest intellectual disability library in the country, providing access to e-books in 2016 for the first time
- A volunteer programme encouraging friendships as well as short-term projects where a person with an intellectual disability can learn a specific skill
- Funds to our Associations throughout the country so that they can make some decisions about what's needed in their own communities.

If you are one of our supporters, either through the Annual Appeal or through our other fundraising schemes, please accept my personal thank you.

Ralph Jones  
Chief Executive



Denise L'Estrange-Corbet (right) with artist Andrea Nowell-Usticke from Clive. Andrea is a regular entrant in the IHC Art Awards and won second prize at the 2013 Art Awards.

## Art Awards move to online judging

This year the IHC Art Awards are being held earlier in the year and the format is changing to make it easier for artists across New Zealand to get their work seen by judges.

We will be calling for entries in April and artists will be asked to attach digital images of their art to their entry forms, rather than sending their artworks to a regional gallery. This way the Art Awards will focus on getting high-quality artwork from the entire country.

Until now, the first round of judging has been held in one of three regional centres, but it has taken a lot of time and resources to hold these regional events and to deliver works to regional galleries for judging. This year there will be no regional events, only the gala night in Wellington where the winners will be announced and the top 30 works auctioned.

In another development, popular judge Denise L'Estrange-Corbet, WORLD fashion director, is taking on the role of IHC Art Awards Ambassador.

Denise has judged the Art Awards six times since 2009.

In her new role, Denise will connect directly with artists preparing to enter the Awards.

“Denise has a special rapport with the artists. We see this as an important role, one that would work more closely with artists and the art bases, helping artists to prepare and enter the Art Awards,” says IHC General Manager of Programmes Janine Stewart.

This year when artists complete the entry form online, they will also have to submit their artwork as a photo attachment to the entry form.

The judges – Wellington artists Gina Matchitt and Grant Corbishley and Auckland art curator and consultant Tim Walker – will each select the 40 top artworks online. These artworks will be brought to Wellington and exhibited at the Arts on High Gallery in Lower Hutt. Here the judges will join forces to select 30 finalists and the three winners.

The 100 selected works will be exhibited for one week at Arts on High and the 70 works not selected as finalists will be available to purchase online.

Entries open on Monday 4 April and close at 5pm on Friday 29 April. The gala auction event will be held on Thursday 16 June 2016 in Wellington.

For more information, please contact [polly.atkins@ihc.org.nz](mailto:polly.atkins@ihc.org.nz)

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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](https://www.facebook.com/ihcnewzealand)

### COVER IMAGE:

Ch'von Matene and her daughters, Bonnie (top) and Olivia Galvan, are the faces of this year's IHC Annual Appeal, which urges support for families of children with autism.



From left, Olivia, Ch'von and Bonnie take time-out with the television.

## Ch'von digs deep into her 'bag of tricks'

Ch'von Matene was living the dream in Sydney with her husband, Dave Galvan. She had a good job in the food industry and Dave ran their own courier and delivery businesses.

There was only one problem – Ch'von and Dave were struggling to start a family. They tried for children for eight years until finally using IVF to conceive two girls. But there was some devastating news to come. Olivia was diagnosed with autism. A year later, so was Bonnie.

The family agreed to front IHC's Annual Appeal this year to talk about the stress and isolation faced by families of children on the autism spectrum. The Appeal asks donors to fund IHC workshops to support these parents and children.

"Olivia was diagnosed when she was four. Bonnie was already a year old ... and you are just devastated. It was almost exactly a year after Olivia's assessment

that Bonnie was diagnosed with autism and severe developmental delays," Ch'von says.

After 17 years in Sydney they gave up their home and businesses and moved back to New Zealand last year to be closer to family support. They now live in Hamilton.

Watching a movie on TV at 1am and waiting for Bonnie to wake up and play is what Ch'von calls her down-time, but it will be another couple of hours before she can finally sleep. "Bonnie tends to get up between 1am and 2am in the morning. She usually just sings and plays and then goes back to sleep about 3am or 4am," Ch'von says.

Late nights and early mornings are part of the lonely, exhausting life of parents with an autistic child. When the girls were small, Ch'von was able to work from home.

"That was fine when the girls were in their cots. But right now the girls are fulltime, whether they are at school or day care," she says.

*Continued on page 9*

Nearly 500 families signed up for free community autism workshops run by IHC last year. Many more are on a waiting list.

There is a very high demand for support for families of children with autism. Government-funded programmes (ASD Plus, ASD Communication & Behaviour, Growing up with Autism) are at capacity and have waiting lists – some families are waiting up to 18 months.

The IHC-funded workshops provide vital advice and connections with other families. They help to ease the loneliness and isolation of parents. The workshops are provided free for families and caregivers.

Since April 2015, 53 workshops have been held across the country in 12 North Island centres and four South Island locations. They cover essential information about ASD and practical ASD support strategies.

For more information about autism and workshops, visit [ihc.org.nz](http://ihc.org.nz) or call 0800 273 7587.



Member Council Chair Barbara Rocco is seeking Council members.

## Volunteers wanted for new Member Council

Barbara Rocco, Chair of the new Member Council, is looking for people to spearhead a move to get members more closely involved in the issues that affect people with intellectual disabilities – and there is still time to be considered.

**B**arbara was appointed as Chair of the Member Council in October and her aim is to create a stronger connection between IHC members and the organisation by making sure their views are represented at Board level.

She has been working with an establishment group to set up the Council and to find members who share her passion for bringing the issues affecting people with intellectual disabilities and their families to the attention of the Board.

This initial 'think tank', made up of IHC Association Chairs and other members met in November to set priorities and suggest how the Member Council will operate. It will meet again this month to confirm the Council's terms of reference, its work programme and to make recommendations to the Board.

Already the think tank has identified the need for improved communications with members and closer working relationships between IHC Associations and IDEA Services staff.

Barbara says the Council's work will touch on both advocacy and service issues and it needs a mix of

people to reflect the diversity of the organisation. Anyone interested in being on the Council still has time to get in touch.

IHC is looking for people:

- Of all ages to represent people at different life stages
- From across the country to get a good spread and mix of urban and rural perspectives
- From different ethnic backgrounds to reflect the diversity of our people
- With first-hand experience of intellectual disability – as a self-advocate, family member or a person whose work brings them into contact with people with intellectual disabilities
- Well connected in their communities and with wide experience.

Barbara will be putting forward a list of names for approval to the IHC Board in April.

If you are interested in being considered, or know someone who would be suitable, please let us know. Send names and contact details to Barbara Rocco at [membercouncil@ihc.org.nz](mailto:membercouncil@ihc.org.nz) or post to General Manager IHC Programmes, PO Box 4155, Wellington 6140. We will send you more information and a form on which to register your interest.



Lena Taliaoa and her children Jasmine and Jayden cut the ribbon at the opening of 12 new units in Christchurch in November, with Rata Foundation Chair Roger Bridge and Accessible Properties General Manager Andrew Wilson (right). Lena had been sleeping in her car with her children and Jayden has major health problems.

## We are helping people into good houses

We are all used to the headlines – we know New Zealand has become a country where too many people are living in poor quality homes or, worse, are living in garages, cars, caravans or on the streets.

**IHC** and its property company, Accessible Properties, already provide good quality, affordable housing for people with intellectual disabilities. In 2010, we set up Accessible Properties so that we could provide accommodation for more people

struggling to find somewhere to live because of health or disability problems, as well as for older people and those on low incomes.

At the end of last year, Accessible Properties was selected by the Government to provide an extra 358 homes in Auckland.

The company will build around 58 new homes and will lease and sublease a further 300. This will be part-funded by government grants.

“Our priority is for people with disabilities, but that doesn’t stop us providing housing for people with other social support needs,”

says Accessible Properties General Manager Andrew Wilson. “We fill our houses from the government’s Social Housing Register and know that there are far too many people in Auckland desperate for a home for them and their families.”

Accessible Properties plans to make sure at least a hundred of the extra homes are available to live in by the end of this year.

“But the need is far wider than Auckland,” Andrew says. “People are desperate throughout the country, but particularly in Auckland, Wellington, Tauranga,

Hamilton and Christchurch – that’s why we jumped at the chance to make a difference in Hamilton and we are closely following the state housing sales process in Tauranga.”

Accessible Properties is about to welcome tenants in 344 more homes, thanks to a deal to purchase the units from the Hamilton City Council. It will receive government Income-Related Rent Subsidies for new tenants, which will ensure that ownership is financially viable.

“We’re looking forward to getting to know the people in these homes and finding out how we can improve things for them,” says Andrew.

Andrew is recruiting two new tenancy managers in Hamilton and is very specific about what he wants. “We look for tenancy managers who are friendly, helpful and have a good eye to know when people need some extra support.”

But he knows the tenants in Hamilton need more than a friendly face. “We’re looking forward to making some changes. We know there’s some modernisation needed and we are looking to add more parking and better access for mobility scooters. Most of all we’re looking forward to getting around and meeting people and finding out what they think the priorities should be. As existing tenants move on, these units will be used to meet a wider range of social support needs, and many are well suited for people with disabilities who want to live independently.”

While the issue of selling state houses remains contentious, Andrew says his organisation’s focus is on whether they can improve conditions for tenants.

Accessible Properties is committed to the process that could see it buy state houses in Tauranga from the



Asnakech Gadissa and her sons, originally refugees from Ethiopia, plant a tree outside their new home in Miramar, Wellington. They had been living with Asnakech’s brother and family in a two-bedroom home in Newtown. After a call from their school, Accessible Properties found them accommodation. The family shifted in September last year.

Government. “This continues to be a slow process,” he says. “But we are putting in the hard yards – the deal would have to allow us to be able to put more support around tenants. Naturally there are financial considerations too – and the availability of government rent subsidies will help. It would need to leave us with enough money to be able to provide that support as well as being able to complete necessary maintenance and improvements.”

Andrew says it’s still too early to tell whether that deal will work but, he says, with such

high demand for good housing, Accessible Properties is still moving on a number of other possible options.

“People are in need and we have the ability to grow the number of homes we can offer them. We’ll keep talking to the Government, to councils and to non-government organisations and other charitable organisations and will do what we can.

“We know our current and future tenants well – and we are committed to doing our bit to support them.”



The cast performs *Master of the House* from *Les Misérables*.

## Curtain went down, smiles lit up

There were smiles all round when the curtain went down on *Both Sides of Our World*, a show co-funded by IHC North Canterbury Association and the Waimakariri District Creative Communities Scheme.

The pre-Christmas production, held in the Rangiora Town Hall, provided people with disabilities an opportunity to showcase their talent alongside other groups of community artists.

IHC North Canterbury saw an opportunity to strengthen community connections and worked with the Rangiora Community Choir, Defy Dance Group and the Dale Hartley School of Speech and Drama soloists and jazz dancers. The result was a professionally produced afternoon of musical theatre managed by IDEA Services staff and a backstage crew from Dale's school.

Lisa Drew, IDEA Services Vocational Team Leader, says it was a positive and overwhelming experience for the vocational team, "who came together with the help and support of many others with vision and passion, believing the people we support can do anything".

For Dale Hartley-Brown it was a first working with a mixed-abilities cast. "I am amazed at how hard they have worked and am grateful to have been able to help create an event that combined such diversity."

North Canterbury Association Chair Kay Pearce says one of the most rewarding moments was hearing the performers talk about how they felt after they had performed. They loved being involved and were left with a sense of happiness and satisfaction.

One performer, Jade Fodie, was able to overcome her shyness to being able to 'own' the stage.



Jade Fodie is very shy – until she gets on stage. Jade performed in *Diamonds are a Girl's Best Friend* and five other numbers on the day.

"Once I got into it I was happy and pleased for my family and the audience. It made me feel proud and glad to be finished."

After the show, Kay was left to sort through the hundreds of photographs. "We get them all printed off and put into albums for the day base and people can purchase their own," she says.

## Legacy funds family 'time-out' research

Trustees of a \$1.9 million fund have launched a research project to ask families caring for people with intellectual disabilities how IHC can help them get some 'time-out'.

Suzanne Downes, a former teacher and administrator with 30 years' experience in special education, is asking families about the kinds of things that would give them a real break. She is working through a list of 100 families in the Manawatu region who have either used the Woburn Family Support Centre or attended an IHC autism workshop. But she is also keen to hear from others.

Suzanne says the scope of the research is deliberately broad. She will be asking families about the kind of pressures they are facing in order to come up with some flexible and creative solutions to ease those pressure points. It could be that a family might benefit from increased access to assistive technology to be able to use online resources with their family member, or be

able to have more one-to-one time with a sibling, or "Wouldn't it be great if I could have a couple of hours a week to go to the gym, but I can't afford a gym membership".

"From the data collected, IDEA Services will be in a better position to understand families' needs and wants, so as to provide quality, responsive respite support in the Manawatu area," Suzanne says.

The research is being funded by the Zena Elsie Orr Memorial Trust fund, which was set up in 2013 with a bequest from Zena's sister, Enid Orr, to provide short-term care for people with intellectual disabilities in the Manawatu area.

With interest, the original bequest of \$1.6 million now stands at \$1.9 million and the trustees are keen to do more than subsidise government-funded services and to respond to what families say they really need.

The three trustees are IHC legal advisor John Hanning, Orr family representative Mark Cleaver, and Ray McIndoe, who has an adult son with an intellectual disability.



Suzanne Downes

They are excited about the possibility of being able to use the Manawatu research as a prototype for respite services in the future.

Enid cared for her sister, Zena, who had an intellectual disability, until she moved into care. Zena was 70 when she died in 1993. The bequest came from the sale of the family farm. The proceeds from the farm sale were invested and the money stayed untouched for decades, gaining interest. Enid left an estate worth close to \$2.5 million when she died, aged 91.

If you are a family in Manawatu caring for someone with an intellectual disability and would like to be involved in the research project, please contact Suzanne on [suzanne.downes@idea.org.nz](mailto:suzanne.downes@idea.org.nz), or phone 06 353 5798 or 027 299 2105.

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## Ch'von digs deep into her 'bag of tricks'

"During the day something will come up. It will either be a call from the school or the day care. Dave and I knew that we couldn't both keep working. It's not fair to us or the girls.

"So Dave – God bless him – works like a dog and I am a lady of leisure. That is what I tell myself, because I have to believe it. We have some great days – and days when it could have been better. All we can do is reset and go again," she says.

When it's a bad day and she can't

distract the girls, they head for home. "Bonnie explodes and Olivia tends to implode and she'll scratch her face and pull her hair, pinch and scratch her arms and whack her head, usually just with her hand and that will escalate and get worse as Bonnie gets worse. So I try to stop Olivia. What works today, doesn't work tomorrow. So we constantly try a lot of things. We have a great bag of tricks. When that is all used up – and we're all used up – we pick the kids up and we come home to the safe bubble," she says.

*Continued from page 4*

Ch'von was hungry for the companionship of the parents she met on an ASD Plus programme run by IHC to educate families. "We were quite sad when it finished. It's a chance to meet other parents because it's a very lonely world. I am just glad that I pushed past the tears and the sadness.

"I am on the list for a communication and behaviour course, but that's a year's waiting list. So much can happen in a day, in a month. A year is a lifetime. A year is too long."



IHC Library staff (from left) Phil Clarke, Ros Booker, Ann Everard and Michael Holdsworth.

## IHC Library investigates digital options

Close to 1000 people use the IHC Library each year but digital technology will make it possible to reach a far greater number, says IHC Library team leader Phil Clarke.

Phil is in the process of introducing e-books, along with a range of other initiatives, to make the library more widely accessible and to help library users build relationships with the librarians. “We have to show them that the library is a friendly place and you can call us up and ask us questions.”

Phil worries that the library, based at IHC National Office in Wellington, is not reaching everyone who needs it. He says more than 50 percent of library users are family members or caregivers of people with intellectual disabilities. “But the bulk of our use comes from the Wellington area, which highlights one of the problems with the library. While we send out items for free, we do require people to return them, so that is a barrier,” he says.

“This is why things like e-books are appealing. They break down that barrier. Anyone can look at them at any time without cost.” It makes it easier for people from all over New Zealand to use the service. Phil wants to introduce 1000 e-book titles and is exploring options with an Australasian supplier.

But e-books are only part of the solution. Other initiatives he is exploring include video guides to

what the library can offer, supplying extracts from books or journals, one-page guides on certain topics, and providing help with searching the web to find accurate information from reliable sources. Phil prefers to think of the library as an information service.

“It’s easy to equate libraries with books; it’s what people do all the time. But a library is about getting the right information to a person at the right time.”

The IHC Library collection includes books, DVDs, kits and journals. Topics covered include autism, Down syndrome, other syndromes and conditions such as OCD, ADHD and Williams syndrome, anger management, puberty, toilet training, self advocacy and resources for and about adolescents.

There are resources for families, our staff, people working in the health system, social work and education, and students. There is also a well used children’s collection which is ideal for explaining conditions to the child and to family, friends and classmates. “In the school space, there is huge potential to have more people aware of what we can do,” he says.

The library is available Monday to Friday 8.30am-5pm. For more information about e-books and other library services, call free on 0800 442 442, or email [librarian@ihc.org.nz](mailto:librarian@ihc.org.nz). The library catalogue is online at <https://ihc.mykoha.co.nz/>

## Andrew was angry at being left behind

Looking back, Rob Hitchin can now see what was making his son Andrew so unhappy. Andrew desperately wanted to live his own life, but he was still living with Dad at the age of 34.



Rob and Andrew Hitchin

A shift into residential accommodation on Auckland's North Shore has given Andrew some freedom and made an enormous difference to the whole family.

Mum Lindy died of melanoma in 2002 when Andrew was 21. "It was one of her wishes when she was dying that he go into residential care," Rob says. But Andrew was grieving and unhappy. "I pulled him out of there because he was very depressed and I felt guilty."

Andrew came home to live with Dad, brother Robert and sister Lauren. Rob, who worked as crew on long-haul flights for Qantas, changed his rosters to be at home as much as possible. But he acknowledges that with son Robert at university, Lauren became one of Andrew's main supports. "Lauren was 14 when her Mum died."

The stress on the family came to a head with Rob's retirement. He became Andrew's fulltime carer only to find that Andrew was becoming more unhappy and hostile towards him. "I wasn't providing him with an environment that he was happy in. I didn't know how to fix that and he didn't know how to fix that," Rob says.

"The guilt is terrible. As a parent it's very hard to step out of the parent role and be objective. I was under a lot of stress. I just didn't know what to do with him. He was holed up in his room. He had seen both his brother and sister marry, move into their own homes and pursue their careers. And he was the eldest, stuck here at home with Dad, with no future."

Andrew started hoarding rubbish in his room, including rotting food, and refused to let his Dad into his room to clean up. Rob would go in when he was out and clear out the stuff that was a health hazard. "I was worried the whole time in varying degrees about Andrew. If he was out and about I would worry that he was safe," Rob says.

A psychologist from Dual Disability and a support needs assessor from Taikura Trust came to assess Andrew and helped the family to find residential support with IDEA Services. "They found a placement for him in Forrest Hill. Andrew and I went over and had dinner with them and straight away he liked it and he wanted to stay.

"He is as happy as a sand boy. He has things that interest him. He has programmes that people are working on with him. He has a wonderful set-up in his room. I can't believe how committed his carers are. He is very fond of the people who surround him. He has given everyone nicknames and that is a good sign," Rob says.

"He wasn't going anywhere. There was no future for him. We didn't know how to go about finding employment for him. Now he has a purpose. He has a reason to get up in the morning. There are of course a few teething issues as we expected, but I can only see it getting better with time.

"I don't have the responsibility any more. I am not Andrew's primary carer; I am his Dad. That is a huge difference. He likes it and I like it."

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### **IHC NATIONAL OFFICE**

Level 15, 57 Willis St,  
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](mailto:gina.rogers@ihc.org.nz)

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