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IN YOUR COMMUNITY

# COMMUNITYMOVES

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**PATRONS**

Dr Roderick and Mrs Gillian Deane

**NEW ZEALAND LIFE MEMBERS**

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Dr Terry Caseley  
Dr Roderick Deane  
John Holdsworth ONZM  
Sir Colin Meads KNZM MBE  
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Tony Shaw

**NZ PRESIDENT**

Donald Thompson

**NZ VICE PRESIDENTS**

Shelley Payne  
Christine Lee

**CHIEF EXECUTIVE**

Ralph Jones

**IHC NATIONAL OFFICE**

Level 15, Willbank House, 57 Willis St  
PO Box 4155, Wellington 6140  
Ph (04) 472 2247, Fax (04) 472 0429  
www.ihc.org.nz

**EDITOR**

Philippa Sellens  
Ph (04) 495 2771, Fax (04) 472 0429  
Email philippa.sellens@ihc.org.nz  
IHC New Zealand Inc  
PO Box 4155  
Wellington 6140  
Ph 0800 442 442

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# From the President



It was great to get together with 28 of the IHC Association Chairs in May in Wellington. I was really pleased to hear about some of the activities that associations are doing. I can

assure those of you who are members of IHC that you have a hard-working and committed group of chair people who undertake a great deal of voluntary work for IHC around the country.

There are a number of projects that Associations are supporting that will make a difference to people with intellectual disability and to IHC. An example of this is the aged and ageing project. It's clear that we really need to focus on how we look after our older people in the future. We have run articles about this in previous issues of *Community Moves* and we will keep you updated.

Another exciting project is the We Can Help project for Christchurch. There's more information about that in this magazine. I would like to thank Associations for their generous financial contributions to this project, which has paid for bedding, clothing and other items to replace what our staff and service users lost in the earthquake and to keep them warm over the difficult winter months.

Over a year ago we committed to modernising IDEA Services' vocational services and I was pleased to hear some positive things about what's happening around the country. Again, many Associations have made big contributions to making their vocational services more attractive and interesting.

I continue to be pleased at the high level of support IHC receives from the community. For example, our annual appeal in February was very successful and I'm very grateful to those people who gave, especially when there are a number of other charities who also have needs.

Membership remains important to IHC. Those of you who are members will have received nomination papers for one Board position and the position of National President. I hope you take advantage of the opportunity to have a say in how IHC is run by nominating someone for the Board and voting. My term is up but I would like to stand for another term. The annual general meeting is coming up on Saturday 27 August at 1pm at Wharewaka O Poneke, Wellington Waterfront (Cable Street). All members are invited to attend and I look forward to seeing those of you who can make it.

Donald Thompson  
National President

# Personally Speaking

June 2011

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I'm writing this column the day after the Budget and the day after the Supreme Court gave permission for us to appeal the Court of Appeal decision on the sleepover case.

On the Budget, I didn't have high expectations of our sector being valued by the Government, so therefore I wasn't disappointed. The extra money given is about a 3% increase for the sector, which will go some of the way to paying our increased expenses such as wages, petrol and electricity, but we will still be out of pocket.

On the sleepover case, we're very happy that the Court agrees there are grounds to appeal, which is what we have believed right through this process. The hearing is scheduled to begin on 13 September.

It's pleasing that progress is being made with the sleepover issue. It has felt to me like over the last two years I've constantly talked about the necessity of government getting involved in this issue. At last they are, and we've been involved in mediation with the unions, government and providers. I realise that we're talking about enormous sums of money, but there has been a determination around the table to resolve the issue so all parties can move on. With both mediation and legal action progressing I'm confident that we will resolve this issue in the coming months.

I need to acknowledge the staff of IDEA Services and Timata Hou through this difficult process. We've always said we wanted to have business as usual, and our staff really deserve credit for achieving that. They have focused on the people in services, and haven't let the issue distract them from the important work they do. They have continued to make a big difference to the people they support and I sincerely thank them for keeping things moving.

There have been signals over the last couple of years that there is a need to deliver services in a different way in the future. I am getting messages from families that there is a need for things to be different. I know there is some anxiety about change but we hope to make it better for people.

I also want to give credit to our staff in Christchurch who have been true champions since the earthquake. Immediately after the quake they got services up and running again quickly, and met the immediate needs of people who could no longer live in their homes, including those in supported independent living. I have visited Christchurch and I know staff are doing a great job despite the enormous hurdles and the stress caused by ongoing aftershocks. Every day is stressful for them, and I thank staff and management for keeping going. This is a time for the whole organisation to help out, and a project is underway to do this. You can read about it on page 6.

Ralph Jones  
Chief Executive

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# A new way to learn skills for life

Timata Hou, the IHC rehabilitation service designed to give people the skills they need to live successfully in the community, is undergoing some changes.



*Clients at the opening of the new life skills building in Porirua.*

A new purpose-built workshop in Porirua is part of a move to refocus efforts to give people the skills to live and work successfully in the community.

At the same time, a new general manager of specialist services has been appointed. Liz Matthews, who starts this month, will have overall responsibility for Timata Hou and other specialist services.

Liz is returning to IHC from Australia where she has been working in Victoria as regional services manager for the EW Tipping Foundation, a non-profit organisation providing community support services to people with disability, children, youth, families and seniors across Victoria. Liz worked for IDEA family/whanau services until 2006.

Timata Hou is a specialist service operating in Wellington and Auckland and designed for people with intellectual disabilities who need more structure in their lives. A number of these people have been referred by the courts; others have been referred for help by NASC needs assessment services. In Wellington,

the service caters for between 20 and 25 people, with 40 overall.

Wendy Rhodes, general manager of quality and special projects says Timata Hou last year identified the need to reshape and restrengthen its life skill and day activities programmes. She says the new life skills workshop provides the right environment to do that.

"The staff and the clients can't help but feel good about that and it will complement the work that has been done to reshape the programme," she says.



*The new editors group at Timata Hou came to national office to collect information.*

Janine Stewart, IHC's general manager of programmes says some people really struggle to live well in the community and need help on the things that cause them stress.

"When we opened the new life skills service, the cultural group was singing and everyone was just absolutely fabulous. They were proud. It's their place and it's important that we keep reminding them that it's they who decide the rules of the place, their expectations and the rules for behaviour."

At Timata Hou programmes are designed for the individual and peer support will be an important way to help people to encourage each other to make changes in their lives. The service also cooperates with other organisations to give service users wider opportunities to build life skills and experiences.

Janine says the new life skills building provides flexible spaces – for computers, woodwork, art and rooms for counselling groups and session. "There is a really good space for movement and creative activities as well. It is a place to go to learn; to explore where your skills are; what your talents are – and it's a place to reflect."

# Quentin and Shaun call it quits

Quentin and Shaun both started smoking in their early teens – but the rising cost of cigarettes has put paid to their habit.



*Cigarettes are past history for Quentin Allen and Shaun Tuffley.*

At the end of last year Quentin Allen, 31, and Shaun Tuffley, 28, gave up smoking. Quentin used to smoke 14 cigarettes a day and Shaun smoked a packet a day and it was having an impact on their health as well as their wallets.

Quentin, who found he got tired if he tried to do anything too physical, is now playing basketball. Shaun's high blood pressure is coming down.

Sheer willpower was Quentin's method for quitting. He bought a pack of cigarettes just before Christmas, told everyone that it was his last pack and went cold turkey. Shaun said he just

stopped because he didn't have any money to buy cigarettes.

The men, who both use Timata Hou services in Porirua, say it's hard to be around smokers and to smell the smoke. "It's quite a temptation when I see the other people having a smoke," Shaun says. He tries to avoid the smokers, and to avoid strong coffee which triggers the need for a cigarette. But they say some of other guys at Timata Hou are trying to give up too.

Shaun, from Napier, started smoking when he was 14 or 15 and used to take cigarettes from his parents' bedroom. He says his mother, who is 50, has heart

problems and is still smoking. "My blood pressure is not that high any more. It was pretty high."

Quentin, from Dannevirke, says his grandmother, who used to be a smoker, kept telling him to give up. She has now died but he encourages his grandfather. "I try and tell my grandfather to give up. I say, 'It doesn't get you anywhere mate'.

"I don't want to go back to it; it makes me sick," he says.

Timata Hou Life Skills Project Manager Alison Hand says they are all hoping to build on Quentin and Shaun's success and encourage other smokers using the service to quit too.

# Gifts to warm the heart and body

Dianne Pelvin was left with only the clothes she stood up in when the February 22 earthquake wrecked her Christchurch home.



*Dianne Pelvin is grateful to be home – and thanks to generous IHC Associations she will be able to keep warm.*

But three months later, when she was finally able to return home, a gift was waiting for her – to say good luck, keep warm and we are thinking about you.

Dianne has been given a Woolrest electric blanket to keep back the chills of a Christchurch winter and the draughts of a damaged house.

In a newly launched 'We can help' project, IHC members from throughout the country are donating money to pay for warm winter bedding and other 'cheer' packages for people with intellectual disabilities living in Christchurch.

IDEA Services supports 507 people in Christchurch and 12 surrounding towns. Many are in close proximity to the epicentres of Darfield and Lyttelton. Thirty-seven residential houses and six day bases are in Christchurch itself.

One house and one day base are still uninhabitable and a number are

without adequate sewer connections and water supply.

Dianne's home in Bexley was hit by both Christchurch earthquakes. The September quake caused minor damage; the February quake left her for months looking for somewhere else to live.

Dianne has an intellectual disability, severe health problems and she needs a machine to help her breathe at night. Going home to a house without power and a working toilet wasn't an option.

"I tried to go down a couple of days later, after the February earthquake, and getting towards where I board I was up to my knees in mud. It was liquefaction – that is very slippery and dangerous. I ended up turning around and coming back.

"The lady I board with and her son stayed in the house. He was in the sleep-out, but he had to move inside. The foundations of the house have

moved; the window frame in my room has moved. The house has received a lot of damage," she says.

"I have a CPAP sleep apnea machine – I need power for that. That is why my support worker got on to her manager and got me moved. I was with my Mum for about a week. Since then I have moved twice to two IDEA Services flats before moving back home this week.

"It has been hard. We are still feeling the odd, strong aftershock. I am a bit jumpy; the slightest things will give me a fright. I have been a little bit down but I have been able to pick myself back up by taking my medication," Dianne says.

"I feel I have coped reasonably well. It's been good being able to get back home. I like living there – it's been my home for four-and-a-half years."

IHC Board member Barbara Rocco, from Marlborough, says staff and people we

support in Christchurch are telling us just how tough it is. "They don't know how long it will be before their lives return to anything like normal. We need to let them know that we haven't forgotten them," she says.

"They are champions – but even champions get tired and need people to encourage them.

"The Christchurch folk are facing winter with power cuts – and that's a struggle when our residential homes are mostly heated with electricity. People are wearing hats inside to keep warm," says Barbara.

"They have to go outside in the cold to use portaloos, or use chemical toilets because they can't flush. And the chemical toilets then have to be carted down the road and emptied into the public waste bins to be carried away.

"The rest of us can only imagine what it's like. But we can try to make things easier – by contributing cash to help them keep warm, to replace damaged possessions, to lift their spirits, to remind them that the bad times will get better.

The Marlborough Association is one of a number throughout the country that has dug into its funds to help.



## Pizza to you – with love from us



*Communications staff in national office try out a sample of the pizza. From left: Amy Watson, Tania McKenzie and Mao Vaireka.*

A plan has been hatched to send feelgood food to Christchurch too.

The IHC Self Advocacy team – with the help of Hell Pizza – is sending pizza vouchers to all the 507 people we support in residential services or independent living in Christchurch.

The team put in \$5340 from its funds to buy vouchers and Hell came to the party with another \$1000 worth of vouchers and free delivery coupons.

National Self Advocacy manager Caroline Barnes says the vouchers will be sent with cards featuring photographs from the recent Christchurch 'Take a Moment with Us' Exhibition that was showing at the Canterbury Museum at the time of earthquake.

*"THEY WILL BE GOING WITH OUR LOVE – AND A NOTE SAYING 'WE'RE ALL THINKING OF YOU.'"*

# Case-by-case approach to productivity allowances

Workbridge and the Ministry of Social Development are clarifying their approach to 'fading out' productivity allowances to cater for people who need ongoing support.

Productivity allowances are paid to employers who give jobs to people with disabilities. But there have been protests about a recent move to reduce the allowance by 5 percent every six months.

In a statement, the Ministry of Social Development says it is clarifying who might be exceptions to the 'fade-out' and how the reviews of the allowance will work.

"The main reason for the change is to free up funding from ongoing subsidies – sometimes for many years for a limited number of people – to provide both subsidies and other forms of support to help a larger number of disabled people into work," the Ministry says.

Workbridge, which administers the allowances on behalf of the Ministry of Social Development, decided in September to apply the 'fade-out' to control the rising costs of the allowance.

Workbridge chief executive Grant Cleland says it was always intended that the productivity allowances would fade out over time, but that wasn't happening.

"Over the past five years there has been a \$2 million increase in the cost of productivity allowances," he says. "While the workplace subsidy was increasing, other more natural supports, which



*Wayne Gaskin chops kindling at the Marton day base.*

encourage independence, were actually decreasing.

Grant says fade-out plans have now been applied to 378 productivity allowances. "For 218 of those, plans have been for a reduction of less than \$20 per week.

"We have had around 20 employers come back to us with concerns." He says as a result of these concerns Workbridge and MSD are taking another look. "We have identified that there is a group of people who may, over a long period of time, require some continuity of productivity allowance."

He says productivity allowances recognise that when someone with a disability starts a new job, they may be a little less productive than others. "As time goes on most should be able to develop their skills, get better or faster at their job.

"This issue gets right to the heart of how we really value the contribution that disabled people can make in our

community. I am a disabled person myself and what I want is that employers value the skills and contribution that a disabled person can bring to a workplace.

"When an employer who is asked to contribute an extra \$20 says, 'Well the person can finish tomorrow,' it illustrates that we do have a problem."

Blenheim Foods owner Mark Witchalls, who employs three disabled staff fulltime, is frustrated at the move to fade out the productivity allowance.

He says it's a "totally unrealistic expectation on the employee. People don't suddenly get out of their wheelchairs or lose their autism. It's going to put a major handbrake on any employer wishing to employ someone with special needs".

Disabled people do become skilled but "you cannot put a time on it. Some people will take six months; some people take years", Mark says.

# The job's been a long time coming

## It's been a long wait for a farm job for Waata Houia, 26, who lives at Opotiki.

When Waata finished high school he and his mum Pam Houia-McGreevy both left home. They shifted from Opotiki to Pukekohe in 2002 because job opportunities for Waata were few and far between in the eastern Bay of Plenty.

In Auckland, Waata enrolled in the PGG Wrightson/Agriculture New Zealand introductory farming skills course. Pam was his reader/writer for the course and 'Camp Mum' to the rest of the students. The move was a success. Waata, at 16, was the first person with an intellectual disability to complete the rural skills programme.

But that next step into a farm job hasn't happened yet. Ten years on, Waata still lives with his mum Pam and step-dad Barry McGreevy and over that time he helped out on dairy farms managed by Barry. Pam says the owner of the last farm, near Morrinsville, and his family were very supportive of Waata and this boosted his confidence.

In terms of other employment though, she says it's hard to get over that initial hurdle of having to tell an employer about the disability. "When we have rung for a job interview and I say, 'I have got a special needs son, people back down and say, 'I am not sure your son would be able to help out.'"

Waata, who has recently returned to Opotiki with Pam and Barry, is an IHC selfadvocacy northern regional representative and his role is to encourage people with intellectual disabilities to speak up. "Some bosses are not user friendly with disabled people on farms," he says. "You have got to get out there and be known and make it happen for yourself."

Mark Witchalls, managing director of Blenheim Foods Marlborough, employs

three fulltime staff, all of whom have a disability. In 2009, he won a Walk the Talk Award at the EEO Trust Work & Life Awards and he has advice for employers who may be reluctant to take on someone with a disability.

He says an employer must take the time to interview the prospective employee properly.

"Ask them if there is anything you need to know – any set of triggers that you might have to be aware of." He says if you can anticipate the stress levels, you can minimise them.

"Make sure that these people can get to work. We are in a semi-rural environment and we have overcome that with carpooling."

Blenheim Foods makes frozen foods for takeaway outlets around the country and Mark has simplified procedures and created a culture so that people with disabilities are supported to be effective employees. Mark says people need time to adjust and learn work skills and they

often need support outside work too in their dealings with various agencies.

Karen Taylor, IDEA Services community service manager in Whangarei, says high unemployment and lack of transport make it difficult for people with disabilities to find jobs, but the biggest hurdle is encouraging an employer to change their attitudes about people with disabilities.

Karen manages supported employment services in Whangarei for IDEA Services. Northland has the highest unemployment rate in the country – at 9 percent (the national average is 6.6 percent).

She says there are a number of barriers, including "needing to convince people that just because somebody has an intellectual disability it doesn't mean that they can't learn and can't be part of the team".

"I think what it boils down to is being responsive and finding out what a person really wants – so making sure that we put them in the right place."



*Waata Houia is waiting for the right job that will use his farming skills.*

# IHC to give families a voice at election time

Families will be given the chance to have their say about disability support in the lead-up to this year's General Election.

Between now and November the IHC Advocacy team will be visiting rural and regional areas throughout New Zealand to hear firsthand from families about what needs to change to make it easier to care for a child with an intellectual disability.

IHC Director of Advocacy Trish Grant says the Advocacy roadshow has so far visited the 'Far North' and Taranaki to listen to families. "Particularly in this year, leading up to the election, it's important that we have relevant, topical and current information to inform our election strategy," she says.

Trish says one of IHC's priorities is to connect with young families who have a child with an intellectual disability. And the team will be mounting a 'Call to Action' campaign on behalf of children who need better support and services than they are getting at the moment.

IHC is also keen to work with families on future planning and dealing with some of the legal 'curly' issues surrounding wills, trusts and consents.

She says from what she has heard from young families so far it is clear that whether they live in the city or in the country, they face very similar issues. "Families were talking about having to educate health professionals about disability."

They were often struggling to get access to paediatricians and other specialists – speech therapists, occupation therapists – "which makes for a pretty difficult situation for these families".

In rural areas families also experience isolation, lack of special education services and find that support generally is not readily available because of the distances from services. "But the upside is that the disabled child and the family were part of the community. There were



*At a recent 'Start Strong' seminar in Wellington, James Voykovich from Auckland, released an armful of balloons representing all the children with intellectual disability in New Zealand who need better support services.*

some great examples of inclusive practice in these rural schools."

However, Trish says the schools were meeting barriers – "there was not enough funding for teachers and teacher aides to travel to training opportunities in other locations.

"I was shocked at the lack of support for many families and children in rural areas. It

confirmed for me that there is a real need for IHC to connect with young families."

Trish says she saw real poverty up in the north and how hard it was for families to travel to find disability services. She says there was a big demand for the services and resources that IHC can provide and it is important that IHC works with children's and community organisations to meet the needs of these families.

# A public tribute for a private supporter

**John Holdsworth doesn't say much about what he does for people, but this private man received a very public acknowledgement in April with an award from Governor General Sir Anand Satyanand.**

John, Chairman of the Datacom Group and Life Member of IHC, was recognised in the New Year honours as an Officer of the New Zealand Order of Merit for his services to business and the community.

He played a major role in changing how IHC handled its finances and its properties, and in shaping the organisation as it is today.

In the early 1990s John was brought in to help with the organisation's finances and during the next 15 years as chair of IHC's Finance and Audit Committee he had a huge impact.

As chair of the Properties Board too, he helped to reorganise the way IHC managed its properties, separating them from the rest of the organisation's service delivery. The change of focus resulted in a huge improvement in the quality of houses throughout New Zealand. His vision was taken one further step last year when IHC set up a separate company,

Accessible Properties Ltd, to manage the organisation's properties.

John served on the Executive Committee from 1995, then as a member of the IHC Board of Governance from when it was set up in 1998 and for the following eight years. He served as New Zealand vice president from 1995 until 2002. In 2007 he was awarded New Zealand Life Membership of IHC.

"He really was an amazing influence," says Jan Dowland, who was IHC chief executive from 1997 to 2001. "He was really instrumental in a much more focused approach to managing all our various systems of revenue."

Jan says the fact that a man who was highly respected in business was advocating for the change was very important. She says he saw very clearly that IHC properties were a significant asset. "He believed because of the scale of the business it needed to be

professionally managed.

"I think he probably contemplated way back then where the journey went. He was very clear about what needed to happen. He was persistent, but he didn't think it needed to happen overnight. The organisation has been really, really lucky to have someone of his experience, his calibre and ability to be an advisor."

John was also involved with the organisation at a grass-roots level, joining the Wellington branch committee and was elected chairperson in the mid 1990s.

His involvement with IHC has also been shared and encouraged by his wife Merrill who this year was awarded Life Membership of the NZ Down Syndrome Association and has been involved for many years in Special Olympics New Zealand, and through their son Michael who has an intellectual disability.

John was behind the first IHC Computer Assisted Learning Centre in 2002. Through the Holdsworth Charitable Trust he funded the computer equipment for the centres at Park Road and the Christie Centre in the Wellington area.

The family has also provided a lot of support to the IHC Library through the Trust, in particular, a major project to upgrade videos to DVD, and to purchase library resources and publicise the library's services.

John has been Chairman of Datacom since 1988 and is the majority shareholder. He was responsible for establishing the company's community and social responsibility programme with the company contributing to many organisations in the region. The company has more than 3000 staff, including 1500 in New Zealand.



*John Holdsworth is invested as an officer of the New Zealand Order of Merit for his services to business and the community by Governor General Sir Anand Satyanand.*

*Photo: Government House.*

# Free book gets families off to a good start

There's now a free gift available to all families who have a baby or young child with an intellectual disability.

IHC and The Freemasons Charity are working together to send a book about intellectual disability to every family and their child who request it.

A copy of *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives*, by Kathryn Lynard Soper, will be sent to parents of children under five years old with Down syndrome.

A copy of *Playing, Laughing and Learning with Children on the Autism Spectrum*, by Julia Moor will be given to families whose child has been diagnosed with autism by a health professional. Autism is generally diagnosed by a paediatrician when a child is between two and four years old.

A third more general book, appropriate to anyone who has a young child with an intellectual disability, will be selected by IHC librarians who are aware of the latest literature.

Books will be distributed from the IHC Library and information about how to apply will also be available from Plunket, the Paediatrics Society, Autism New Zealand, New Zealand Down Syndrome Association, Early Intervention Trust, Parent 2 Parent and many other partners. The Freemasons Charity is funding the project.

"We are hoping that the project will help IHC to connect with families right from when their child is very young," says IHC

***Do you have a baby or young child with an intellectual disability?***



You won't have much time to sit back with a cuppa and a book. However, IHC and The Freemasons Charity have joined together to give all New Zealand families with a baby or young child with an intellectual disability a free book. We hope the book will be relevant and helpful to you.

To receive your free book you can fill out the information on the back of this poster, email [librarian@ihc.org.nz](mailto:librarian@ihc.org.nz), phone 0800 442 442 and press 4 for the library, or go to [www.ihc.org.nz](http://www.ihc.org.nz) and search for keywords "free book".

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The Freemasons  
Charity  
*a tradition of caring*



Library team leader Cherie Walker. "People applying for the book will also become members of the IHC library, which is funded entirely by generous donations from New Zealanders."

To find out more, you can email the IHC library on [librarian@ihc.org.nz](mailto:librarian@ihc.org.nz), call 0800 442 442 and press 4 for the library, or go to [www.ihc.org.nz](http://www.ihc.org.nz) and type 'free book' in the search box.

# Amber Rose gets ready for a changing world

Amber Rose McGillicuddy-Hall might be growing up on the same South Wairarapa dairy farm that her great-grandparents worked – but sometimes it doesn't feel like it.



*Amanda Hall with daughter Amber Rose are encouraging families to read more about disability.*

The summer is still as hot and dry, the wind still blows in both directions – from the north and then the south – but now the neighbours grow grapes and olives. The once-isolated town of Martinborough has become the centre of one of the country's most successful wine-growing regions and a 'go-to' destination for wine, food and music lovers.

The world is opening up for Amber too. She is fronting a new IHC book donation project for families who have a child with an intellectual disability. Amber, 20 months, was born in September 2009 with Down syndrome.

The family lives about 5 minutes south of

Martinborough. They farm a 70-hectare property and milk a Friesian-Jersey herd alongside the Ruamahanga River. Amber's grandfather Kevin, now in his 80s, still helps clean up after the milking.

Their association with IHC started a long time ago. Kevin McGillicuddy began donating calves to the PGG Wrightson IHC Calf & Rural Scheme right from the beginning of the fundraising scheme, 27 years ago. For all that time the scheme has been supporting people with intellectual disabilities and their families in rural areas where services are often scarce.

Amber's parents continued the family tradition when they took over the farm not

knowing, of course, that one day Amber might have use for the kind of support that IHC can offer. Her mum, Amanda, is already getting familiar with IHC's Wellington-based library that offers phone and online services to people anywhere in country.

These days the family donate a 'virtual calf' because the local sales are no longer held in Masterton and it's easier than trucking a calf to Feilding.

To find out more about the PGG Wrightson Calf & Rural Scheme or the book donation project call 0800 442 442 or visit [www.ihc.org.nz](http://www.ihc.org.nz)

# Trish rides a wave of success

Trish McQueen's determination to succeed in sport and her ability to inspire others has combined to win her a further honour – the 'Personality of the Year Award' at the 2011 Kapiti Sports Awards in early May.



*Trish and her supporters at the gala dinner*

When Trish competed in the Kapiti Women's Triathlon earlier this year she was swept along on a wave of support from people wanting her to achieve. She then celebrated cheerfully with 'Team Trish' and all her other supporters in the Kapiti community, on the coast north of Wellington, where she lives and trains.

Trish's sporting achievements led to nominations in two awards categories: for Athlete with Disabilities and Personality of the Year Award – the award she went on to win.

One of the nominations came from Team Trish manager Michelle Laurenson who told the judges Trish "has an infectious personality".

Michelle paid tribute to Trish's commitment in the lead-up to the

Kapiti Women's Tri. "In December, Trish completed the Kapiti Harriers 5km walk in an impressive 55 minutes. In January, with her support person, she entered the Scorching Bay Triathlon but Trish still completed the run despite the driving wind and rain.

"In a remarkable endurance performance Trish completed the AMI Wellington Round-the-Bays 7km walk/run in February. She had crashed off her tricycle the evening before and spent several hours in hospital with a suspected ankle fracture, but she was just bruised and she was able to complete the walk the next day.

"All these events were building up to the ultimate show of great stamina in the Kapiti Women's Triathlon at the end of February," Michelle says. "She had a



*Triathlete Trish McQueen was named Kapiti Sports Personality of the Year at a gala dinner in early May.*

support person but swam, biked and walked the full event."

Trish knows everyone and never forgets a name. "Walk with her round Coastlands to see how popular she is," Michelle told the judges. "She's a great ambassador for sport and to all in the community for her cheerful spirit and determination."

On awards night Trish celebrated with Team Trish – Louisa Gaimster, Michelle Selby and Jan Crafts – the three Kapiti women who ran, swam and biked alongside her at the triathlon on February 27. Also celebrating with Trish was David Corner, IHC self advocacy coordinator and IHC volunteer coordinator Jacquie Harrison. Jacquie put Team Trish together after she went looking for volunteers in Kapiti keen to help an aspiring fellow triathlete.

# Communication is key to good design

An expert in designing homes and services for older people says it's critical to keep the dialogue going between the staff who support residents and those who design the buildings.



*Colm Cunningham calls for good communication between support staff and designers when planning homes for older people.*

Colm Cunningham, director of the HammondCare Dementia Centre in New South Wales, was in Wellington in April to speak at an IHC workshop about good design principles in housing for older people with intellectual disabilities.

The design workshop, part of IDEA Services' Successful Ageing Project, was attended by staff from Accessible Properties, IDEA Services and the Successful Ageing Project team.

Colm says while there is a lot of debate going on, there are some guidelines emerging – for example, how the use of colour and light and types flooring can make life easier for older people. He says there has been plenty of research done on the ageing eye in the general population and this has led people to suggest that a contrasting colour can work as cues for people. "Simple things like choosing to have the bathroom door a different colour may be the thing."

He says residential staff may notice that someone is not eating well, or losing

weight – that might be because they cannot see their food. "The research shows that the lux [light] levels that would be standard for someone in their 30s or 40s would need to be about double for a person in their 60s or 70s."

Colm says he once visited a well-designed unit for older people. "The chief executive was showing me around and he said, 'I don't know why it's so light in here and he started turning the lights off.'" But Colm says it was clear the unit had employed staff who knew the importance of good lighting.

Having the right flooring was important too. "The evidence is extremely strong that if a floor is highly polished and looks shiny and wet, or if a floor has a lot of pattern on it, then people with dementia might slow down. People with Down syndrome already have some problems with 3D perception – that is increased with onset of dementia. If you have a contrast, then the person might feel as though they have to step over something when they are trying to get to the toilet pan."

Colm says good design doesn't have to be expensive and might be included in a maintenance budget. "Maybe all you have to do is to paint the tiles around the back of the cistern.

"A lot of services have sought to deinstitutionalise – in doing so, we are trying to create environments that are more relaxed and modern." But he says when someone is getting older with intellectual disability and dementia, then their needs change.

"I think that the critical things are those core concepts of keeping the environment predictable, calm and encouraging visual access," he says.

"The biggest trap I have found in my work is the lack of communication between

the people on the ground and the people designing the facilities."

He says there has not been a lot of research done on the impact of ageing and dementia on people with intellectual disabilities and he is encouraged to see the work being done by IHC. He is keen for that to be tested and to be shared internationally.

Workshop convenor Nigel Smith, from Accessible Properties, says the intention is to draw up design guidelines for housing that will meet the needs of people as they age. This will be done as part of the Successful Ageing Project. He says the design guidelines are in the early stages and the workshop had given participants a lot to think about.

IDEA Services clinical director Sharon Brandford, sponsor for the Successful Ageing Project, set the context for Colm's presentation by updating participants on progress of the project.

"His workshop was an opportunity we wanted to take advantage of because we knew our services were grappling with what interior and exterior design challenges worked best for people as they aged. We wanted them to get advice from the best in the field," she says.

Andrew Wilson, general manager of Accessible Properties says, as a result of the workshop, the company was planning to review its design consultation processes to make sure they are comprehensive and that decisions are made by managers with appropriate accountability.

He says Accessible Properties is also planning a follow-up session. This would happen once the Successful Ageing Project has done its work, so that building designs could be tailored according to what the project team recommended.

# Kenneth Cumberland – pioneering geographer and devoted dad

Pioneering geographer Kenneth Cumberland, who died on April 17 at the age of 97, was a reserved Yorkshireman. But the support staff who helped care for his daughter Sheevaun saw a devoted, affectionate man.



*Kenneth Cumberland with a photograph of his daughter, Sheevaun, who was the inspiration for the Pukekohe home that was named Cumberland House. Picture NZ Herald.*

Sheevaun had Down syndrome and was in IHC residential care for almost 40 years. Tanya Cumberland, Kenneth's younger daughter, says mother Marjorie played the major role in Sheevaun's care until her death when Sheevaun was 19. Marjorie died at 49 from a cerebral haemorrhage. After that "Kenneth became the rock," Tanya says.

"We were faced with that terrible decision about what was going to be good for Sheevaun. I looked after her for three or four months at home, but then we all realised that she needed special care. She went to the Masonic-IHC Lodge, a community home in Papakura."

Tanya says her father didn't find it easy to communicate with people. "Kenneth was really shy; he had no small talk. Some people found him difficult to get close to," she says. "He was actually quite a reserved Yorkshireman."

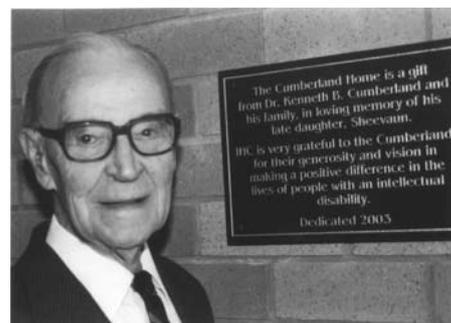
But with Sheevaun it was a different story. Every Sunday he would collect her and take her home for the day. On the

way back to the residential home in the evening, he would buy her a Topsy ice cream. "He was absolutely superb with Sheevaun and he showered her with all the love and affection."

In 2003, Kenneth donated a purpose-built, six-bedroom home for older people with Down syndrome in Pukekohe, now known as Cumberland House. He had planned the Reynolds Road home as a place for Sheevaun to live, but she died before the home could be completed. He dedicated it in memory of Sheevaun.

"She died unexpectedly of apnoea in her sleep. She was 59. When she was born Mum and Dad had been told she wouldn't live much beyond 20," Tanya says.

Cumberland House was the first purpose-built home in New Zealand for older people with intellectual disabilities. When the home opened in 2003, Kenneth said: "Sheevaun's generation of people of intellectual disabilities are living longer and new facilities are needed to support them in their ageing process."



Kenneth arrived in New Zealand from England in 1938 and was followed by his younger cousin Maurice Carter to Christchurch. Tanya says their mothers were twin sisters and "we called them brothers and soulmates". He is credited with making geography popular in New Zealand and revolutionising the subject in schools after writing resources for teachers.

In 1946 he moved to Auckland to take up a position as Senior Lecturer in charge of Geography at the Auckland University College. He became the first Head of the Department of Geography at the University of Auckland. He was the first geographer to be elected as a Fellow of the Royal Society of New Zealand.

He left the university in 1978, and became widely known in New Zealand after he wrote and presented the ground-breaking Landmarks television series in the early '80s. In 1983 he was awarded the CBE for his services to education and communication.

Kenneth and his first wife Marjorie had three children and in 1991 he married again. Both Marjorie and his second wife Rene died before him. He is survived by two of his children, Tanya and Garth, and grandson Barnaby. His cousin Maurice died two weeks after Kenneth at the age of 93.

# GET CONNECTED –

what IHC Associations are doing

## Expo a combined effort in Dunedin

A combined effort between the Otago Association, IDEA Services and family/whanau services led to a highly successful Disability Expo in Dunedin last month.

With over 200 people attending the free Expo and 30 paying stallholders, the response far exceeded the organisers' expectations.

IDEA Services Otago Area Manager Daniel Barnett said that they were very pleased with the response from local organisations and businesses that work in the disability sector. The Expo was sponsored by Smith City, which also had a stall, and the Dunedin City Council.

Stall holders included Special Olympics, the Halberg Trust, mobility scooters, People First, the IHC library and the Deaf Association.

"There aren't many opportunities for organisations and businesses in the health and disability sector in Dunedin to get together to promote the services they provide. We did a lot of networking on the day of the expo," says Daniel.

"For example, we found out the Special Olympics have a new initiative where they give free health checks, so we'll now be promoting that especially among people in supported living."

Daniel said the venue in the Otago Museum was handy for Dunedin's large student population to visit. In hindsight, one of the improvements Daniel would make to the stall was to promote employment opportunities at IDEA Services.

Family/Whanau manager Joy Harvey agreed that the expo was a resounding success.



At the expo from left: Joy Harvey (IDEA Services family/Whanau manager), Daniel Barnett (IDEA Services Area Manager), Helen Collie (IDEA Services family/Whanau Regional Service Manager), Jan Stevens (IHC Association Chair)

"It created a wonderful opportunity for Family/Whanau to get our name throughout Dunedin, in a very positive manner. It was a great chance for me to become familiar with other services that are available in Dunedin and to share that with families who use our services. There was certainly many hours work in the months leading up to the expo but seeing it up and running and receiving such wonderful feedback definitely makes it all worthwhile."

Dunedin Association Chair Jan Stevens said that the Association provided some financial support for advertising, prizes and refreshments and some administration. It also collected items for the "goodie bags" and put them together.

She agreed that a key benefit of the day was to meet with others in the sector and people who are interested in what IDEA Services and IHC does.

"One of the positives in the Otago area is that the Association has a very good relationship with the IDEA Services Area Manager and Family/Whanau and we work well together for the benefit of the organisation and our service users," says Jan.

"On the day the highlight for me was the opportunity to meet with others in the sector and also find out about some newer groups that I was not aware of."

Jan says that the day was a big success, and the question isn't whether another Expo will be held, but when - either next year or every two years.



One of the stalls at the Expo in Dunedin.

# GET CONNECTED –

what IHC Associations are doing

## Association Briefs

### WHAT'S COMING UP FOR ASSOCIATIONS AND MEMBERS

**Annual general meeting:** The annual general meeting is coming up on Saturday 27 August at 1pm at Wharewaka O Poneke, Wellington Waterfront (Cable Street). All members are invited to attend.

**Board nominations:** Those of you who are members will have received nomination papers for one Board position and the role of National President.

It's a chance to take advantage of the opportunity to have a say in how IHC is run by nominating someone for the Board and voting.

**Any queries please contact Danette Wilson, 0800 442 442**

#### **NZ Volunteer Awareness Week 19-25 June 2011:**

This week is an excellent opportunity for IHC to show how much we truly appreciate all the work our volunteers do, whether involved in the one-to-one friendship programme or as part of an Association committee. You are all volunteers and integral to the work we do to advocate for the rights, inclusion and welfare of all people with an intellectual disability.

Volunteer coordinators around the country are hosting small events to say 'thank you' to volunteers. It would be great to see people from the Associations there so you can be thanked.



*General Manager IHC Programmes Janine Stewart, welcomed the new National Manager Volunteer and Community Development Adele Blackwood and introduced her to association chairs.*

**IHC membership: please send back your membership renewal for the 2011-2012 year.**

### CHAIRS SIT DOWN TOGETHER

A meeting of Association chairs, due to take place just a few days after the Christchurch earthquake, finally took place in mid May.

Around 28 of the 36 current Association chairs met for a day to share information, and get some ideas and instructions on how to run their local Association.

The day began with presentations from IHC Chief Executive Ralph Jones and National President Donald Thompson. In his presentation Ralph updated chairs on some of the issues facing the organisation this year.

Donald thanked chairs for making a contribution to IHC. "IHC's associations of members are the vital face of IHC in our communities. You have the opportunity to do really practical things in your local communities that can't be done at a national level.

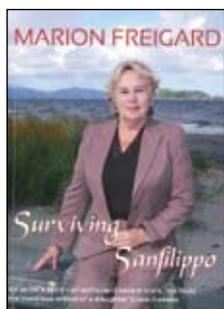
"More and more the Board is recognising how important our community presence is, and that it can't be done by paid staff. The community-focused activities provided by associations of members are what our local communities see," Donald told the chairs.

General Manager IHC Programmes Janine Stewart introduced Adele Blackwood, the new National Manager of Volunteering and Community Development. Part of Adele's role will be to support Associations.

A presentation about the aged and ageing project was made by Clinical Director Sharon Brandford.

In the afternoon all chairs attended clinics on communications, getting the most out of their Association, and finances.

# What's new at the IHC Library



## *Surviving Sanfilippo*

*Marion Freigard*

Marion Freigard's autobiography spans her experiences growing up in England, her move to New Zealand, her daughter Jo's rare progressive illness and, finally, life after Jo's death. In this bold, sometimes harrowing, account Jo and her terminal condition are central themes that govern Marion's

life and that of friends and family. There are moments of wry amusement and candid personal revelation that give relief to the continuous hardship of caring for a daughter in such distressing circumstances. Marion's strength and personal tenacity come from the support and understanding she has received along the way.

ID 27592 2010

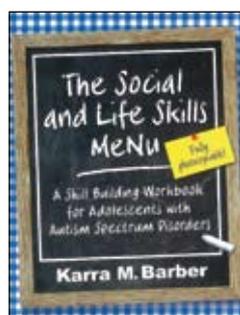
Surviving Sanfilippo is available at Almo's, Carterton; Dymocks, Westfield, Lower Hutt; N.Zique, Jackson Street, Petone; Unity Books, Wellington.

For libraries: All Books, Christchurch; and Total Library Solutions, Auckland

Quote: ISBN 978-0-473-17867-3

Also: signed limited edition hardback illustrated poetry book Heart and Soul (limited number available) ISBN 0-473-06799-4

Enquiries: freigard@xtra.co.nz



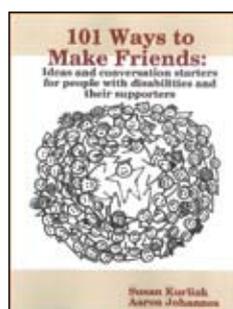
## *The Social and Life Skills MeNu: A Skill Building Workbook for Adolescents with Autism Spectrum Disorders*

*Karra M Barber*

Written by the parent of a child diagnosed with Asperger's syndrome, this book is designed to help individuals on the spectrum become proficient in social communication skills and life

skills. Using a play on words 'Me and You – MeNu' this book starts with the fact that most social conversations develop between two people. Using a restaurant menu as a template, this book guides readers through each step of a conversation, with 'starter' statements to initiate conversation, 'main course' topics to talk about and 'treats' that bring the exchange to a close. Social scenarios encourage students to think through their responses and consider the consequences of what they say and how others might react. Reproduced by permission of Jessica Kingsley Publishers

ID 27492 Jessica Kingsley Publisher 2011



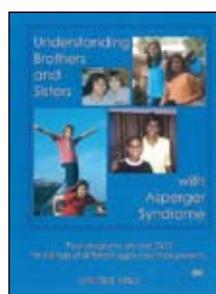
## *101 Ways to Make Friends: Ideas and Conversation Starters for People with Disabilities and their Supporters*

*Susan Kurliak and Aaron Johannes*

The authors have taken ideas from conversations with individuals and groups of people with disabilities to develop this book. It is packed with examples about what to do and

where to go to find friendship. Ordinary situations are used and explained and, as the title says, there are 101 of them. The illustrations are appealing, as are the easy one or two-line sentences and the positive attitude found throughout.

ID 27493 2010



## *Understanding brothers and sisters with Asperger syndrome*

This DVD contains four programmes for siblings of children with Asperger syndrome and their parents. Each programme covers a range of challenges and strengths, and describes techniques siblings can use to get along and support each other. Parents can show their children the programmes that best suit their

age and developmental levels, from age four through to adult. Although intended for siblings, this DVD would make interesting watching for anyone wanting to understand Aspergers.

ID 26448 Coulter Video 2007

## From the web

Some URLs that may be of interest.

Family stories from the Australian Association for Children with a Disability website will support, inspire and surprise ...

[http://www.acd.org.au/noticeboard/story\\_main.htm](http://www.acd.org.au/noticeboard/story_main.htm)

This next one from the Encouraging Families with Exceptional Children Together website shows what is achievable when people reach out ...

<http://www.efect.org/>

You can contact the library on:

Free phone: 0800 442 442

Email: [librarian@ihc.org.nz](mailto:librarian@ihc.org.nz)

Online catalogue: [www.ihc.org.nz](http://www.ihc.org.nz)

Facebook

<http://www.facebook.com/IHC.NewZealand>



**COMMUNITY** *MOVES*

