

StrongVoices

EMPOWERED LIVES

Winter 2023



**Eyes fixed on
the fairway**

**Footballers will
make history**

Lorde says thanks



Kōrero

Last year, IHC asked some specialists to measure the impact of our Family-Whānau Liaison programme in changing lives. Thanks to two generous IHC donors, we commissioned a Donor Impact Report on our Family-Whānau Liaison work in Whangārei.

This was a brave new world for us, and we were a bit fearful about whether analysing our front-line work through a numbers and data lens would completely miss the important human interactions and impact of this programme.

We collected all the non-identifiable data and information we could for the ImpactLab data analysts reviewing the programme, showing the number of people supported, the number of interactions and outcomes over a 12-month period.

The result has been so worthwhile in helping IHC to identify how we collect data and understand outcomes and impacts, and how we could get much better at it. The report showed that every \$1 spent on this programme provided a social return and positive impact of \$2.10.

We also know that as we get better at measuring and capturing key data and outcomes, this social return on our donors' investments will be even higher.

We are very grateful to Glenn and Sonja Hawkins, who suggested doing this report and funded the costs.

I know how important it is for each of us as donors and supporters to see what impact we are having. There is a transaction in fundraising: a donor gives money to a cause they really care about and in return they want to feel they have had a positive impact – someone has been helped, someone has a better future, our community is a better place.

The great thing about this impact report is that it not only measures that impact, it helps us get much better at understanding the difference we are making.

We know about the excellent work done by people on the front lines of our work, like Jim Callaghan, our Family-Whānau Liaison in Whangārei, but it's so good to have the impact quantified in a scientific way and get some great insights into how we can do things even better.

This is our first ImpactLab report at IHC. There will be others over the coming years.

I love being part of and raising funds for an organisation that wants always to improve on our work and impact. It's so good for our wonderful donors to have confidence they are making a lasting difference to the lives and futures of people with intellectual disabilities. This is part of our IHC fundraising transaction and our promise to our donors to deliver positive impacts effectively in the community.

Greg Millar
National Manager, IHC Fundraising

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Capture the Moment

Do you love taking photographs of our beautiful Aotearoa New Zealand?

Send us your best shots for our Capture the Moment competition by 5pm on Friday 30 June.

You can win cash – \$2500 for the overall winner and \$1500 for the Youth Award – and have your work exhibited as part of the Hastings visual art and cultural FOTOFEST.

www.ihc.org.nz/capturethemoment

Join the conversation:

We want to keep you posted. Be the first to read the news and views across the IHC Group and disability sector. We'd love to hear from you.

 facebook.com/ihcnewzealand

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 www.ihc.org.nz/strong-voices

Cover image:

Courtney Ratana tried his hand at golf and found his new happy place at the Manawatu Golf Club. See the story on page 9.

Back page image:

Christchurch volunteer Rebecca Hillery (left) and Anna Cross first met in 2021 and enjoy getting out for shopping and a movie.

Member Council Chair understands what drives parents

IHC

The new Chair of the IHC Member Council, Lynne Renouf, comes with 45 years' experience as an activist.

Lynne joined IHC when her son Duncan was born with Down syndrome and has made her presence felt at every level of IHC, pushing for change for Duncan and many others.

She says she doesn't like being part of an organisation if she can't get involved in decision-making.

Lynne is a former IHC Vice President and Board Member, and former Chair of the IHC Board Advocacy Advisory Committee. She has been a member of the Kāpiti-Mana Branch Committee and Association for 30 years, including serving as President and Vice President. Lynne is also an IHC New Zealand Life Member and is a recipient of the New Zealand Suffrage Centennial Medal 1993.

Duncan was about six months old when Lynne had her first encounter with IHC in 1978. She had a visit from Wellington branch member Jean Clarke, who wanted to know if the family was managing all right. In those days IHC received referrals from Plunket. Jean was the mother of Campbell, a disabled son

born 30 years earlier.

Turning up to her first IHC mums' morning tea in the Porirua East Community Centre, Lynne knew she had found her people. "We immediately started talking, made terrible jokes and in the end had a hilarious time," she told Julia Millen, the author of the IHC history *Breaking Barriers*.

Lynne says she understands what drives parents – and that it's something different for each generation. The parents who came before her wanted to keep their children safe.

"I was part of a group of parents who wanted something more. We were fighting to get our kids into school, so we fought the Education Act." The Education Act was changed in 1989, with Section 8 giving every student who had special educational needs the same rights to enrol and receive education at State schools as those who did not.

Lynne was working as a relieving teacher when Duncan was born. "It didn't occur to me that he wouldn't be going to the local kindergarten. I just took him when he was three and a half." He stayed there until he went to Porirua East School, a primary school with a new satellite class attached to the Kapi Mana Special School. His secondary schooling was at Mana College. "Duncan never wanted to leave college."

Nor did Lynne and her group of parents want their children going to sheltered workshops after they left school, so they pushed for day services 'hubs', and one of the first was a purpose-built day base in Porirua, Te Wa Huri Huri. It closed during the pandemic. Duncan, who attended Te Wa Huri Huri, died in 2017.

"So I identify with parents who want something different," she says. "If I was a 30-year-old parent now, I would be wanting quite a lot of stuff."

"If I was a 30-year-old parent now, I would be wanting quite a lot of stuff."



For many years Lynne has been welfare guardian and property administrator for two wāhine Māori. Both women were born in Porirua and placed in IHC foster care as young children.

“As they reached 20 years, I was appointed welfare guardian and property administrator. Their start in life wasn’t flash,” she says. Their contract carer effectively became their parent.

“Recently the two blended families and moko moved to Ruatoria – before three

months of rain made gumboots the footwear of choice. They are surrounded by very supportive whānau.”

Lynne also holds an enduring power of attorney for an elderly friend who has been supported by IDEA Services since her teens, and she has acted as a ‘friend in court’ for other people with intellectual disabilities who have got on the wrong side of the law.

Lynne says when people work together then disabled people can live their

best lives in the community. She says it’s a team effort. “The Mana-Kāpiti Association have been together as committee and friends for 30 years.”

Lynne’s challenge now is to guide the Member Council through some changes. She is a member of a working group that is looking at the roles and scope of the Member Council and Associations.

Three new members joined the Member Council for their first meeting in April. They are Denise Mackres, North Harbour Association committee member and Op Shop Manager; John Rossbotham, who was treasurer for the Wellington Association for eight years; and Keith Rea, the former Association Chair of the Waikato South Association and now current treasurer.

“The Mana-Kāpiti Association have been together as committee and friends for 30 years.”



Opposite page: New Member Council Chair Lynne Renouf will guide the council through some changes.

Top: Lynne and Duncan in 2003. Lynne became a member of the IHC Board that year.

Left: Lynne and her husband Dick had two sons, Kris (at left) and Duncan. Duncan, born in 1978, was among the first children with intellectual disabilities who went to mainstream kindergartens and schools. He died in 2017, three years after his father.

Families wait for arrival of Rett drug

SECTOR

New Zealand families are celebrating the release of the first drug to treat the severe neurological condition Rett syndrome, and wondering if they will see it here.

The drug, Trofinetide, has been approved by the United States Food and Drug Administration. It went on the market in April.

Rett syndrome is a rare genetic condition that occurs almost exclusively in girls, affecting their ability to speak, walk, eat and breathe easily. It is characterised by constant repetitive hand movements.

Rett syndrome is caused by errors in the MECP2 gene, which inhibit the formation of a molecule essential to cognitive and motor function. Movement and communication skills stagnate or regress after the first six to 18 months of a child's life.

Rett families in New Zealand have a special connection to the drug. The molecule that led to its development was created here 20 years ago at the University of Auckland by a small team of chemists led by Distinguished Professor Dame Margaret Brimble.

Dame Margaret was working with three chemists, David Callis, Nick Trotter and Paul Harris and alongside biologists Associate Professor Jian Guan and Professor Mike Dragunow. They had been looking for a treatment for brain injury.

Their synthetic molecule didn't work for brain injuries, but scientists working for University of Auckland company Neuren Pharmaceuticals investigated its potential to treat Rett syndrome and it eventually became the basis for Trofinetide. Neuren took the drug into phase two clinical trials and then partnered with US company Acadia Pharmaceuticals to carry out phase three trials.

Successes in clinical trials have included girls walking or talking for the first time. Acadia is marketing Trofinetide in the US as Daybue.

"We obviously have been awaiting the outcome of trials and we are very pleased it's on the market," says Rett New Zealand Trust Chair Dugald MacBrayne. "But we are still quite a bit in the dark about what it will do. If and when it becomes available, then we will certainly put our hands up."



Dugald and Christine's daughter Mandy is 40 and has Rett. They are not sure what the drug might mean for her. "Mandy has never spoken – we had a couple of words out of her. What we would wish for is a better level of response," Dugald says. "Mandy understands a great deal of what we say but cannot respond to us."

The drug will likely undergo trials in Europe and in Australia before being assessed by Pharmac here. Dugald says the biggest obstacle to Pharmac funding is the small number of people here likely to benefit.

In an interview with University of Auckland's *UniNews* magazine, Dame Margaret said she was hoping the drug

would get Pharmac approval to enable New Zealanders to be treated.

"While there might only be around 40 to 60 Rett patients in New Zealand, this drug was painstakingly developed over many years by many New Zealanders and a New Zealand company, Neuren Pharmaceuticals, which started here at the University of Auckland, so I'd really hope it can be used in this country.

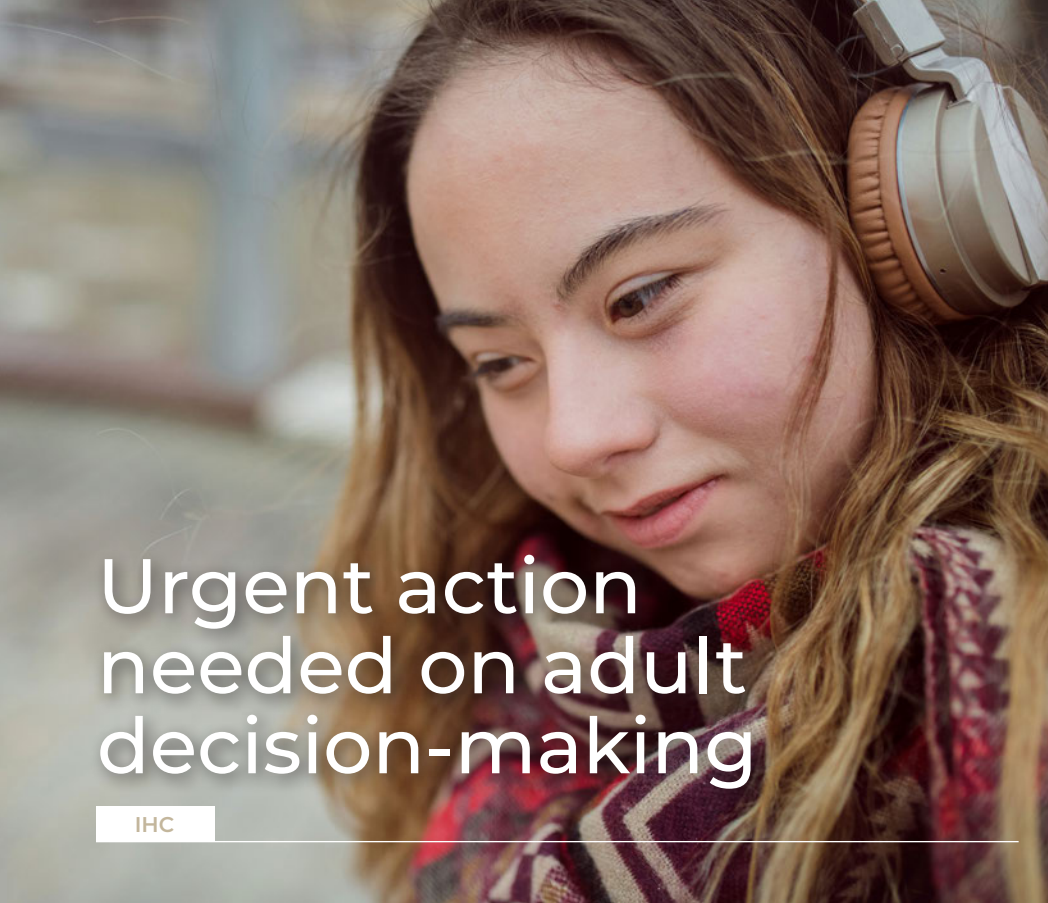
"Obviously, having created the key molecule, I've followed its progress into clinical trials closely and understood the importance for Rett syndrome patients," says Dame Margaret.

"Obviously, having created the key molecule, I've followed its progress into clinical trials closely and understood the importance for Rett syndrome patients,"



Above: Mandy MacBrayne shares a smile with her mum, Christine. Christine and Dugald MacBrayne hope that the new Rett drug will mean Mandy can communicate more easily.

Left: Distinguished Professor Dame Margaret Brimble.



Urgent action needed on adult decision-making

IHC

IHC is urging the Law Commission to protect the rights of vulnerable adults to make their own decisions.

In a submission to the Law Commission's review of adult decision-making capacity law, IHC says the importance of adults being able to make their own decisions, with appropriate support, cannot be understated.

"A person's dignity is severely undermined by substitute decision-making; their safety can be compromised, as well as their ability to respond to and navigate unsafe situations," it says.

"One of the huge gaps in the current system is support for people who do not have family or friends to help them make decisions. For many intellectually disabled people there are no friends, family, or whānau available." The submission says many of those in residential care only have their staff to support them to make decisions.

IHC says it has been contacted many times by various service providers about what is available for people in these situations. Their staff are concerned about the lack of long-term, non-professional relationships for these people.

"If New Zealand is to continue with substitute decision-making, there are additional safeguards needed before it is decided that a person needs a welfare guardian. Capacity assessments must be more thorough than a 'tick box'; they

need to consider the different types of capacity that people may have, and they must be completed by people who have the time and the knowledge to properly assess the capacity of an adult."

IHC says welfare guardians need mandatory training on what being a welfare guardian involves, including an understanding of human rights and the need to involve the people concerned in all decisions.

Welfare guardianship should be reviewed every three years, with the presumption that it will end unless there are very good reasons for it to be extended, and the person concerned should always be involved in the application process with the opportunity to have their say.

People under welfare guardianship must also be able to challenge their guardianship without needing access to large sums of money.

IHC would like to see the establishment of a Public Advocate, backed by an independent statutory body, to advocate for adults who need decision-making assistance, mediate disputes about adults with decision-making needs, and investigate situations of potential abuse, neglect and exploitation of adults who are at risk of harm. "This is a significant gap in New Zealand, and it needs to be addressed by a properly funded national system."

Read the full submission at ihc.org.nz/get-involved/advocacy

Man trapped in catch-22

A man in a supported living service, who wanted to challenge a welfare guardianship application, had his access to funds to pay for it blocked by his welfare guardian.

IHC

In a case study provided to the Law Commission, IHC described how the man had a welfare guardianship arrangement in place, but there had been little examination of whether it was needed. The man was living a very independent life.

The man was unable to access his own funds to challenge the guardianship because a court-appointed property manager was limiting access to the man's money. He needed the funds to pay for a proper capacity assessment, rather than the 'tick-box form' and basic GP assessment provided to the court to continue his welfare guardianship.

The man did not get on with his welfare guardian (and property manager), who lived in another country and was unavailable at times for consultation. The man's repeated requests to the appointed lawyer to challenge the welfare guardianship application went unheeded.

Because he couldn't access his own funds, IHC loaned the man money to pay for a proper capacity assessment, which showed he had capacity in many areas. This allowed him to hire his own lawyer to oppose the welfare guardianship application and ensure that he was able to participate in the court process and regain legal control of his life.

IHC says there were failures at all levels of the system in this case.



Win or not, these footballers will make history

SECTOR

New Zealand's football team has left for the Special Olympics World Games in Berlin where, winner or not, it will make history.

Whatever the outcome of the tournament, it is the first New Zealand team made up entirely of footballers with intellectual disabilities to compete in the seven-a-side event. In previous World Games, New Zealand has competed in the Unified Cup competition, which includes players without an intellectual disability.

The team is planning an all-out attack strategy at the games, which are being held from 17–25 June.

Head Coach Matt Woodason, from Otago, says the footballers are a bit nervous about playing against global powerhouses like Germany and Brazil, but he is impressed with the quality of his players and is confident they can cause a few upsets.

"Looking at our squad, it looks like Todd (Neal, Hutt Valley) will be in goal and the rest all want to be strikers, so we may need to have a chat with the boys that we need to do a bit of defending against some of those big teams," says Matt, who was asked to help his local Special Olympics club 13 years ago and like many volunteers got hooked.

The 11-strong football team makes up nearly a third of the New Zealand squad of 39 athletes, supported by 22 coaches and volunteers. The squad was to leave for Germany in early June for a pre-tournament training camp near Munich.



More than 7000 athletes from 190 countries will compete in 26 sports in the world's largest inclusive sports event, the top competition for athletes with intellectual disabilities.

The football games will be played in and around Berlin's famous Olympiastadion, constructed for the 1936 Olympic Games.

The Olympiastadion will also host the sold-out opening ceremony with nearly 80,000 fans welcoming the teams to Berlin.

"We hope to play in the main stadium, but we are still waiting for the final schedule and opponents," says Matt. The first four days of competition will be used for grading to determine the divisions in which each country will compete for the medals.

"Of course, we are going there to win, but I have told the boys that our first aim is

to score a goal," says Matt, who has been preparing a team scattered all over the country.

"As we only have a couple of training camps, it will be hard to work on their skills, so we have been focusing on moulding a team and talking about not having any regrets. As long as our guys give it 100 percent, it doesn't really matter where we finish," says Matt.

Many of the New Zealand squad have paid employment and have been very busy saving and fundraising to pay the \$18,000 each athlete needs to contribute towards travel, accommodation, training camps and support staff.

Special Olympics New Zealand does not receive Government funding, but Otago footballer Sheamus Neilson has managed to raise the entire sum by himself. "He works at Farmlands, and they have been terrific and chipped in \$5000 to help Sheamus get to Berlin," Matt says.

Above: Finn McNally, from Hamilton, gets some game time before heading to Berlin.

Left: The Special Olympics New Zealand football squad at a pre-World Games training camp. Back row: Matt Woodason, Shane Hewitt, Kyle Scandlyn, Louis Edwards, Conor McCarthy, Todd Neal, Bruce Neal, Ryan Ziad. Front Row: JP Roux, Matthew Just (no longer attending the World Games), Connor Spinks, Ash Coley, Finn McNally, Cole Jennings.



Excitement builds as IHC Art Awards judges go to work

IHC

As entries close for the 2023 IHC Art Awards – the 20th year of the national competition – the attention shifts to this year’s judges who will make their call on the winners.

Our judges for 2023 are Tim Walker, Mark Hutchins-Pond and Elizabeth Caldwell. Each brings enormous experience and understanding of art in Aotearoa New Zealand to this year’s awards.

For 20 years, the artists have been wowing audiences with the beauty and diversity and power of their work.

“It’s the fresh and often totally unexpected work the artists create. And the beautiful energy the process always brings in buckets,” Tim Walker says.

Tim is an Auckland-based arts and culture consultant with more than three decades’ experience in the art gallery sector. This will be Tim’s fourth time judging and he says the IHC Art Awards are a highlight for him.

Mark Hutchins-Pond has extensive art sector expertise acquired over three decades of studying, writing, presenting, critiquing and championing the best contemporary fine art in the country. He is now an art specialist at Webbs after a decade as the contemporary art lead curator at the Pātaka Art+Museum in Porirua.



Elizabeth Caldwell is Te Ringa Auaha, Director Art and Heritage at Experience Wellington, and she is responsible for the oversight of the conceptual content of the exhibitions at all its sites, including City Gallery Wellington Te Whare Toi and Wellington Museum. Elizabeth received an ONZM for her services to the arts in the 2023 New Year’s Honours.

An exciting trend is the number of younger artists entering the competition since the Youth Award was introduced in 2021. Last year Kāpiti student Helena Brocklebank won both the Youth Award and the L’affaire People’s Choice Award for her comic drawing *Angry*. More than 400 people entered the awards in 2022.

In another development this year, we will be exhibiting all the entries from artists in our pop-up gallery at 69 Willis Street, Wellington. This means everybody has the chance to sell their artwork in the gallery. Any artwork that does not sell in the gallery will be listed for sale on Trade Me. Artists will receive 100 percent of the sale proceeds.

The judges will not be selecting a Top 100 this year. Instead, they will select the 30 finalists, including the first, second, third and Youth Award winners from all the entries received. Members of the public can vote for their favourite artworks in the L’affaire People’s Choice Award.

The IHC Art Awards are open to people aged 13 and over with an intellectual disability or an intellectual disability and autism. The prizes are \$5000 for the winner, \$3000 for second place, \$2000 for third place, \$1500 to the Youth Award winner and \$2000 for the L’affaire People’s Choice Award winner.

Above: Helena Brocklebank’s drawing *Angry* (extract) was a concept drawing for a comic series she was working on.

Below: Judges (from left) Tim Walker, Mark Hutchins-Pond and Elizabeth Caldwell (photograph by Celeste Fontein).





Courtney's fairway to the future

CHOICES

When Courtney Ratana is hitting golf balls on the green anything seems possible.

"I want to go to the Special Olympics," he says. "I want to be the next Tiger Woods."

And thanks to the good sorts at the Manawatu Golf Club – and a surprise gift – he's well on his way.

Courtney revealed an early interest in golf only a few months ago when he was walking with Choices New Zealand Life Coach Leander Tyacke. Leander is a representative golfer and they got to discussing the sport.

"Court mentioned he used to play golf with his dad and that he really liked it," says Leander. "So I took him down to the Pro Shop at Manawatu Golf Club one morning and they let us smack a few balls around."

It wasn't long before Courtney was hooked and after a while his enthusiasm was noticed at the club. He was invited to join the club's volunteer men's group, which meets every Tuesday morning in all weather to repair divots, rake bunkers and generally help the greenkeepers. They finish off their hard work with plenty of coffee and sausage rolls.

Courtney gets himself to the golf course every Tuesday and enjoys the camaraderie. "I've made a lot of new friends," he says. "Wayne is my best friend."

Wayne is part of the men's group and often takes Courtney out on the course. The greenkeepers have their own golf

tournament and Courtney is invited along to play nine holes.

Golfing can be an expensive pursuit with club memberships and golf clubs priced into the thousands. However, Manawatu Golf Club General Manager James Lovegrove saw how focused Courtney was and presented him with a complimentary restricted junior membership. And things were to change dramatically for Courtney due to the generosity of one of its members.

"There was this one day where the golf club flag flew at half-mast," Leander says. "We found out that one of our members, Greg, had died. It turns out he'd left his golf clubs, trundler, golfing gloves, jacket and golfing shoes to Courtney.

"There was a handing over ceremony. Greg's nephew and family had come over from Scotland and formally presented Court with all this gear. I had to walk out because I cried."

The gear is very important to Courtney, so he has a safe place at the club to store his golf clubs and he takes his golf shoes home every day to clean them.

It's been just over six months since Courtney first chatted to Leander about golf. But he is not content to stay still. "That's our next move," says Leander. "How to get Court to the next Special Olympics and back."

Now that Courtney has the gear, the club support and the drive (both on and off the course), it seems like the obvious next move.

Strong Voices featured a story about Courtney last year when he started a job at Palmerston North's Lido Aquatic Centre. He still works one day a week at the Lido, is learning to skateboard, and has recently moved into a flat with his friend Stephen.

Above and below: Courtney has found a sport he wants to focus on and a group of friends to help him do it.





No one had a bigger heart than Gwen Kirkwood

Gwen Kirkwood always gave credit to the people of Matamata – a town with a huge heart for people with intellectual disabilities. But the truth was that no one had a bigger heart than Gwen herself.

In 2008 Gwen turned 80 and wondered if it was time to hand over some of her responsibilities with the IHC Matamata Area Committee. By then she had been volunteering for 39 years. Gwen said: "I often thought, when I get to 80 I will need to give up and let someone else take over, but I will go on while I can contribute. I will perhaps fade away before I pull out."

But she never did pull out. Gwen died in January this year, just short of her 95th birthday. As recently as September last year she drove to the IHC Waikato South Association Annual General Meeting.

"Gwen parked as close to the building as possible and independently, with the aid of only her walking stick, joined the group," says Association Chair Annette Davidson. "The people we support were so thrilled to see her, as she was to see them. The only difficulty came when after the meeting Gwen was ready to go home. All the IHC vans had parked behind and beside her little car – she was totally hemmed in. Gwen said she was happy to wait in the car, so this lovely lady waited for quite some time until the drivers of each van could be located."

Annette says Gwen dedicated herself to many organisations. "It just wasn't about all that she did – which was extraordinary – but it was who she was, her personal qualities. She was so full of compassion, kindness and gentleness, which was reflected in her love and caring concern for other people."

Gwen's daughter Wendy recalls growing up around the 'IHC family'. "Mum would go to the centre every day, sometimes twice, do nearly all-nighters for the bake sales, go to the IHC balls, go on working bees, organise and count up for the appeals, go to the meetings, type up the minutes on her portable typewriter. She would sometimes get me to go down and help.

"She avoided the limelight and always redirected praise to others. Dad would often grumble that if he had 'put Mum to work in a real job' we would have been millionaires. He would comment that Mum was never home, but we knew he was proud of her."



Despite her many attempts to deflect praise, Gwen was honoured by the Crown – she received a Queen's Service Medal in 1996. She was honoured by IHC – she was Patron and Life Member of the IHC Waikato South Association. She was honoured by the town – in 2012 she was awarded the Paul Harris Fellow Award by the Matamata Rotary Club for outstanding service to Matamata for more than 60 years, and in 2017 received the Margarett Golding Award from Inner Wheel International.

From 1969 until 1998 Gwen was secretary of the area committee. She continued as treasurer and correspondence secretary until 2017, when the committee was integrated with the IHC Waikato South Association. She joined during a time of intensive activity. The town had got behind a Matamata Lions Club project to build an IHC pre-school in Station Road. The building cost \$16,500 and the Lions raised \$7800 of that. Forty-five local tradesmen donated their time over several months. The pre-school opened in 1970 and the building is still used by IDEA Services.

Gwen and her husband Jack epitomised the IHC/Lions Club partnership. Jack was a member of the club until his death in 2012. The Lions supported the IHC Annual Appeal, and the annual Lions/IHC Golf Tournament raised funds for 50 years.

Gwen wrote hundreds of cards on behalf of IHC. She wrote a personal thank-you to every volunteer who helped at the street stall and Opportunity Shop, and letters to all the schools that provided helpers for the Annual Appeal, to the Lions Club for transport, to bank tellers who helped with the count, and to rural coordinators.

Gwen ran the IHC door-knock appeal for 37 years. She also organised the IHC volunteers at the town's Opportunity Shop and the annual street stall.

When IHC set up its Keypoints services

monitoring system in the late 1990s, Gwen visited IHC facilities in Matamata, Morrinsville, Pūtāruru and Tokoroa.

"Behind that was a strong determination that people in our Matamata community were included and supported," says Christine Lee, a long-time fellow IHC volunteer and IHC New Zealand Life Member. "For Gwen, it was a quiet ongoing thing in the way that she lived. To have a strong voice, you don't always need a loud voice."

Gwen and Jack lost their first two children, Peter at 15 months and Ann at 18 months, due to a brain condition. Gwen and Jack did not say much about their own experience, only that it made them very concerned about people who had disabilities.

Gwen said in a 2008 interview, "My main interest is in the people themselves and their quality of life. Are we enhancing it, are we helping them, are we doing all we can to give them a better quality of life and to be involved in the community?"

Gwen's support of her community wasn't confined to IHC. She said, "In life, you have a commitment to your marriage, to your children, to your church." She was a member of St Andrew's Presbyterian Church in Matamata, serving on the church's board of managers for 40 years – and on the Association of Presbyterian Women for 60 years.

Gwen is survived by her son Robert and Felipa, and her daughter Wendy and Selwyn. She was grandma to Peter, Ruby, Trent, Jack and Sasha, and great grandma to Beau.

Above: Gwen and Isabel Meta celebrate IHC's 70th birthday in 2019.

Opposite page: Gwen working at the Matamata Opportunity Shop in 2019. For years Gwen organised the roster for the IHC week at the Op Shop and provided morning tea for the volunteers.



A master class in making life easier

IHC

Sometimes when life is hard, it can be good to spend time with people who make things look easy.

In April, 18 Auckland family carers and parents were treated to a cooking demonstration hosted by chef Peter Gordon at his Homeland restaurant and cookery school in Westhaven, Auckland

The event was arranged by IHC Auckland Family/Whānau Liaison Anna Wong to give those caring for family members with intellectual disabilities some time out.

The Family/Whānau Liaison team holds two carer wellness events a year in each of our regions. Anna says carers and parents like to try new things but often don't have the time or energy to organise anything. "So it was nice to just turn up and have a fun activity organised for them."

The day started with coffee and tea, and scones straight out of the oven, then it was all action for the next four hours.

"We prepared and cooked lamb stew, kumara miso mash, pavlova (using Peter's Mum's recipe) and feijoa pudding."

Peter would demonstrate and then each table would have a go. The cooking was made easy with Homeland staff measuring all the ingredients and, best of all, no one had to do any dishes. The staff whisked away all the dirty utensils, pots and crockery.

Once the work was done, the participants got to sample the food.

Peter Gordon was based in the United Kingdom for 31 years and ran a series of successful restaurants before returning to New Zealand in March 2020 – just before the first lockdown. He created Homeland with his partner Alastair Carruthers in November 2020.

Homeland, where possible, only uses ingredients sourced locally or from the Pacific Islands.

He believes creating delicious meals with seasonal vegetables will help combat the increasing prices of food, especially as the cost of protein becomes more expensive.

"Peter told us how much he enjoyed sharing his love of food with different community groups," Anna says.

The community days are sponsored by Beef + Lamb NZ, and the lamb for this event was donated by Carve Meat Co. The rest of the ingredients are sponsored by Homeland and there is no fee for the community groups.

Anna says Peter shared his own story of how IHC helped to support his family. His Aunt Mary had lived in an IHC home for a number of years so he was delighted to have us bake his Mum's pav recipe in memory of her.

When Peter's paternal grandfather, William, passed away his grandmother, Mollie, decided to acclimatise Mary to IHC care. As a young person Mary

had attended school for a period, then Wellington Aftercare as a teenager and younger adult. Mary initially lived at Kristina in Silverstream, then in various supervised flatting situations in Silverstream and Upper Hutt. Mary eventually lived at Clouston with flatmates who were firm friends.

While at Clouston, and until her death, Mary was supported by her caregiver Narja Macintyre. Over the years Narja escorted Mary to many family functions and the Gordon whānau considered her an honorary whānau member. They are forever grateful to Narja.

The family says that throughout Mary's IHC experience her interests were applauded and accommodated – crafts, knitting, embroidery, playing cards and board games. The IHC programme was wide and varied, and Mary experienced some wonderful trips and events, and lived a full and varied life.

Above: A day out in the Homeland kitchen was a chance to relax, enjoy good food and learn from master chef Peter Gordon.

Menu

Tilly's pav
Lamb stew
Kumara miso mash
Feijoa steamed pudding
Salad – leaves and apples





IHC Foundation targets funds to greatest need

IHC FOUNDATION

The IHC Foundation was established as an independent charitable trust by IHC in 2007 with an endowment of \$18 million.

Over the past 16 years the investment portfolio has grown to more than \$30 million and has paid out nearly \$7.7 million for projects to improve the lives of people with intellectual disabilities throughout New Zealand.

Using the income from its investments, trustees have funded projects across the sector as diverse as employment initiatives, connecting families to services, sport, the arts, and research into applying modern genetic techniques to the diagnosis of rare disorders. They have also devoted funds to safeguarding vulnerable people through personal advocacy support.

The Foundation focuses on projects that help people to reach their potential, build skills and health and well-being, and develop self-esteem and leadership.

Bevan Wallace, who took over as IHC Foundation Chair last year, says

trustees are keen on projects that offer opportunities for young people to develop life skills. For example, they have supported the Duke of Edinburgh's Hillary Award and Outward Bound to expand their programmes to include disabled young people.

The Foundation has also funded the Christchurch integrated dance group, Jolt, to develop its Move tutor training programme led by dancers with intellectual disabilities. And the decision to fund acting coaching for Libby Hunsdale, the young star of the movie *Poppy*, was in line with the trustees' desire to encourage role models.

Extra funding was provided during the pandemic to help organisations maintain their links with the people they supported.

Bevan says the trustees were proud to support an initiative that partnered Autism New Zealand and Victoria University of Wellington in a play-based therapy programme called the Early Start Denver Model. This collaboration led to the relocation of the Wellington Autism Clinic from the university to the community at the Autism Resource

Centre in Petone.

Since 2009 the Foundation has funded advocacy work by Rare Disorders NZ for a better recognition and funding of these conditions. This helped to persuade the Government last year to develop a national strategy for rare disorders.

Bevan says one of the most enjoyable evenings he had last year was attending a film premiere of a production by Te Whare Ako and Silver Noodle Soup Film and Theatre Company at Mana College in Porirua. The production was *The World Premiere of our Very Cool Film*. Thirty-five students participated in two inclusive filmmaking projects funded by the IHC Foundation.

"It was a red-carpet function. They had fellow students as the paparazzi taking photos. Their parents were there. Their teachers were there," Bevan says. "The evening was more than just a celebration of the individuals who each walked the red carpet and were interviewed and photographed. The evening demonstrated true camaraderie among the students that had no doubt been forged in part by participation in the project."

Last year the Foundation paid out \$788,935 in grants. Forty-one applications were received and 29 projects were successful. These included two Auckland cafés that each received \$40,000 to train young people with intellectual disabilities and support them into paid employment. A \$38,000 grant went to Special Olympics New Zealand for its Young Athletes programme in Auckland.

“It gives me heart that we can allocate additional resources into the sector,” Bevan says.

There has been a recent change in investment approach for the board of trustees. Last year the Foundation entrusted the management of its portfolio to three asset managers, which will relieve its trustees from having to make day-to-day investment decisions. “That has freed us up to concentrate on strategic issues and focus on grants,” Bevan says.

Another major change is the departure of Executive Director Jan Dowland, after 14 years. Jan has worked in the health and disability sector for more than 40 years in research, policy, management and consultancy roles. She is a former Chief Executive of IHC.

“We are incredibly indebted to Jan for her guidance and foresight,” Bevan says. He credits Jan with encouraging sector partnerships and coaching applicants in how to refocus their projects in order to be successful in obtaining grants.

Jan says it has been a great pleasure to see the Foundation develop from inception to now. “The generosity of IHC NZ Inc in making the bold decision to establish and endow an independent grant-making entity is to be applauded.

“We have been able to apply funds beyond the immediate ‘IHC family’ to benefit many thousands of people with intellectual disability and their whānau. Our approach to grant-making has gradually shifted as we think more strategically about where we can make the biggest impact, focusing on particular areas of neglect and areas of greatest need.”

Larna Harding is succeeding Jan as Executive Director. Larna started her career in the banking sector, joining the IHC Programmes team as a part-time administrator in 2008. Larna began providing administration support to the Foundation in 2016. She has a good understanding of the challenges faced by the disability sector and of the work of other disability organisations and

government agencies.

“I have been fortunate to have spent the last seven years working closely with Jan Dowland and the IHC Foundation trustees and to have the benefit of their extensive experience of governance and the administration of charitable trusts.”

Larna has also developed an extensive network within the sector. “I consider it a privilege to work for a foundation that is committed to making a meaningful contribution to the sector and, most importantly, the lives of people with intellectual disability, their families and the people and organisations who support them.”

“It gives me heart that we can allocate additional resources into the sector,”

Opposite page: Mana College student Hinerangi Collins-Mohi has her moment on the red carpet with the paparazzi at the premiere of the Te Whare Ako and Silver Noodle Soup production.

Below: Zariah Gay does a stand-up with Susan Williams, an actor, comedian and performing artist, who was MC for the event.





Students follow another path to success

IHC FOUNDATION

Students who might finish secondary school with no formal qualifications are now leaving with awards that recognise their skills and community connections.

At present students with intellectual disabilities are taking advantage of an alternative pathway to success by enrolling in the Duke of Edinburgh's Hillary Award.

The award encourages young people to develop skills that help them and their communities. Students can progress through three levels – Bronze, Silver and Gold – designing their own challenges based on their interests and ambitions. Participants take part in physical challenges, volunteer in the community, work with social enterprises and gain skills that can lead to employment opportunities.

The Duke of Edinburgh's Hillary Award celebrates its 60th anniversary in New Zealand this year and while it has always been available to disabled students, it has started developing a programme that enables more young people to use the framework more effectively.

In 2021 the IHC Foundation gave a \$20,000 grant to the Duke of Edinburgh's Hillary Award to expand this adapted programme for young people with intellectual disabilities. A second grant of \$20,000 was made in 2022.

To deliver the adapted programme, the Duke of Edinburgh programme partners with schools and disability

support organisations. There are around 20 schools and organisations that cater purely for intellectually disabled students throughout the country.

The Duke of Edinburgh Award Coordinator at Mana College, Cam Fraser, says, "The Duke of Edinburgh's Hillary Award has been a game-changer in terms of offering qualifications that our disabled students might not otherwise gain. Many of our rangatahi will leave school without even NCEA level 1, which sadly will close many doors for them. The award shows to others what they are capable of, and it is something they can continue to work at as they move into their next phase of life."

In 2021 YES Disability Resource Centre became a partner of the Duke of Edinburgh's Hillary Award. YES Disability launched the award in Auckland for young people with disabilities, to help them on their personal journeys of self-discovery, responsibility and commitment.

In 2022 YES Disability supported seven participants through various levels of the award, with four certificates gained.

Louisa Kelly, Programme Coordinator for Manaaki Ability Trust, has run the award for the past four years. Louisa, an award-holder herself, knows the value of the programme. "These guys could really benefit from this – a programme that acknowledges and understands their thirst for life."

Louisa advocates for learning beyond the classroom: "Academic studies have often

limited student success, but the award shows that there much more to life."

The Duke of Edinburgh's Hillary Award Chief Executive Emma Brown says: "Through the generous support of organisations such as the IHC Foundation, more and more young people with intellectual disabilities have been able to discover their infinite potential through the award. We have been honoured to be able to work on this programme with a range of incredible organisations across Aotearoa, and we look forward to continuing to build upon it in the years to come."

Prince Philip launched the Duke of Edinburgh's Award scheme in 1956. Seven years later the award was launched in New Zealand.

With the death of Prince Philip, Prince Edward, the present Duke of Edinburgh, is now patron of the Duke of Edinburgh's Award and the Duke of Edinburgh's International Award.

Above: A team from Manaaki Ability Trust practise the hill climb and fitness training for their Bronze Adventurous Journey over the Orongorongo Track, with an overnighter at Turere Lodge. (From left) Karen Cabezas, Lacey Collier, Conor McCarthy, Louisa Kelly, Patrick Whittaker, Emma Kelleher, Lucas Whittaker Tovey, Stephen Bell-Cummings, Sheldon Valster, Michael Langley and Johnny Fidow Mose.



Philip's journey finally took him back home

IHC

Philip Poulton was 10 years old when he went to live in Kimberley Hospital in Levin in 1967. He was the second eldest of five children from a family farming at Rangiwai Station at Kumeroa, near Dannevirke, and he had Down syndrome.

His parents, Wilfred and Susan, struggled to care for him as he got older and as younger siblings arrived, but once he was placed in Kimberley as a state ward, they were discouraged from visiting and advised to get on with their lives.

Philip spent the next 18 years isolated from his family, until one day in 1989 his younger brother Tim and his wife Annie went to see him. They had married that year and Annie says she wanted to find out more about the secret brother

who nobody talked about. Not long afterwards, Tim and Annie were back to introduce him to their 14-day-old daughter Sian, who shared a close bond with Philip from then on.

Philip died in January this year, and at his funeral Tim described how his parents had cared for Philip through those early years but with five children under 10 the family had needed more help. IHC was only a fledgling organisation in the 1950s and the Poultons were isolated from support on their hill country farm.



“Philip would have loved the silly hat gathering and being surrounded by his friends.”

“He was becoming harder to manage as he grew older and stronger,” Tim says. “All through our childhood, teenage and young adult lives he was essentially erased from our family life, and I feel a deep sense of regret for this to have happened.”

By the time of Tim and Annie’s first visit, Philip had moved from Kimberley into IHC community residential care in Carterton and Masterton. From then on visits to Rangiwaiu became a regular part of his life as he and his family



reconnected. Philip would travel by bus from Wairarapa and be collected at either Pahiatua or Woodville on a Friday evening before returning on a Sunday evening.

Annie says everyone was Philip’s friend – including total strangers, especially if they had bald heads, which he loved. He also loved hats and could wear up to four at once. He had a passion for Tui-branded merchandise and for photography. She says the advent of digital photography was a blessing, and recalls once getting a roll of film developed to find 36 images of washing going around on a washing line.

Over time, Annie’s connection with Philip led to involvement with the local IHC committee in Dannevirke. Annie is now Chair of the IHC Dannevirke Association.

Because Philip had Down syndrome, he aged very quickly and in 2018 moved to an IDEA Services residence in Dannevirke, the closest he had lived to home and family in many years.

His funeral service was attended by his family, friends, housemates and staff from IDEA Services in Dannevirke, Wairarapa and Manawatū, many of whom wore one of Philip’s many hats to celebrate his life. But the celebrations didn’t stop there. The Dannevirke IHC Association

committee had for a number of years wanted to hold a combined disco for the people they supported.

Annie says it has been their goal to expand the social circles of those in supported living in Dannevirke by inviting people with intellectual disabilities from neighbouring regions to join them for an afternoon of fun and music.

COVID restrictions hindered their plans, but on Saturday 4 March the Dannevirke Knox Church hall was rocking to the sound of Dave Barber’s disco and around 75 people were wearing creative hats and showing their moves on the dance floor. Most had come from homes run by IDEA Services in the Manawatū, Dannevirke and the Wairarapa.

This inaugural gathering was in memory of Philip. “Philip would have loved the silly hat gathering and being surrounded by his friends,” Anne says.

Opposite page: Sian, Philip, Annie and Tim share good times at Rangiwaiu Station.

Above: Margaret Fisher, the winner of the silly hat competition at the Dannevirke disco, was one of Philip’s many friends who wore his photograph on a T-shirt.



Lorde says thanks with tickets to her concert

IHC

It might have been Lorde's Solar Power tour, but the sun was shining on Emma at the Western Springs concert in Auckland in March.

Prize-winning artist Emma White entered her portrait of Lorde in last year's IHC Art Awards and the singer heard about it and offered Emma two tickets to her concert. Emma's mum, Diana, scored the other ticket and both of them bought new dresses for the occasion.

It was a huge week for Emma, who had just moved from Te Kūiti on the Thursday



before the concert to a new flat with a new service provider in Te Awamutu. Then it was off to settle into the Rydges Auckland hotel and get ready for the concert. Their accommodation and transport were donated.

They arrived with a blanket and snacks and grabbed a place on the grass in time to hear Marlon Williams and the Yarra Benders. Lorde came on at 8.30pm and Emma was more than ready to hear all the new material live. "I have got the new songs on my phone," she says.

What Emma wasn't ready for was the fact that Lorde appeared with blonde hair. "I have never seen her with blonde hair. I am going, 'Why has she got blonde hair?'. I like her brown hair and not blonde hair." Emma said last year she had found painting Lorde's portrait "quite tricky ... because of lots of layers and colours in the hair".

Emma's passion for music inspires her art. She won third prize and \$2000 for her acrylic painting *Portrait of Lorde*. In 2021 she also won third prize for her *Portrait of Amy Winehouse*. Her works have included Lady Gaga and Prince.

A smaller print of her latest portrait has been sent to Lorde as a thank you.

"I have never seen her with blonde hair. I am going, 'Why has she got blonde hair?'. I like her brown hair and not blonde hair."

It wasn't just Emma who enjoyed the concert. "It was amazing. I would call it magical," Diana says.

"We made sure we were there a good half-hour before Marlon Williams started. Lorde is just absolutely amazing."

Diana says Lorde talked about her insecurities when she was young. "She talked a lot about being different. I felt Emma was in the right place.

"Emma loved it. A lot of the girls had butterflies painted on their faces and she was one of them."

Above: Diana (left) and Emma White soaked up the sun and the music at Lorde's Solar Power concert at Auckland's Western Springs.

Left: Emma won third prize for her painting *Portrait of Lorde*. A print was delivered to Lorde.

There's always a welcome at Lee's place

ACCESSIBLE PROPERTIES

“When someone knocks on the door to ask for some sugar, we always give more,” says Lee Taniwha (Waikato Tainui, Ngāti Maniapoto), who is always ready to help his Accessible Properties neighbours in Auckland.

Lee, Nick Davis and Vaka Leha'uli live in Accessible Properties houses next to each other down a lane in South Auckland.

All three are wheelchair users and their homes have been built so it's easy for them to get around, with wide halls and doorways and wet-area bathrooms.

Nominated by Nick, Lee has won an Accessible Properties Good Neighbour Award and he says they look out for each other. “We hang out and catch up, have barbeques, that sort of thing.”

A summertime accident at a family member's pool when he was 13 is the reason Lee uses a wheelchair. Diving in, he hit the bottom and broke his neck, in an instant rewriting his future.

Before moving into his Accessible Properties home eight years ago, he lived with his dad. The only accessible



room was his bedroom, making day-to-day activities much harder and more time-consuming.

Lee says it's great to be able to get around his Accessible Properties home easily in his wheelchair.

Accessibility makes a huge difference to people's lives and as a member of Te Whatu Ora Counties Manukau Consumer Council and a disability advocate for Auckland Transport, Lee has done a lot to support much-needed change in disability services.

Change is part of Accessible Properties' kaupapa too. We continue to increase the number of our properties that meet the needs of people with disabilities, helping build stronger communities where everyone has the opportunity to belong and thrive.

Above: Lee Taniwha is the right kind of neighbour.

Founding Chair of Accessible Properties joins Business Hall of Fame

ACCESSIBLE PROPERTIES

Sir Paul Adams, KNZM, the founding Chair of Accessible Properties, will be inducted into the New Zealand Business Hall of Fame in August.

Sir Paul chaired Accessible Properties, a 100-percent-owned IHC company and the second-largest social housing provider in New Zealand, from 2010 until 2018.

He is one of seven laureates announced by the Young Enterprise Trust. The others are property developer and businessman Ted Manson, ex-Telecom chief Theresa Gattung, former Auckland Business Chamber boss Michael Barnett, Ngāi Tahu tourism leader Wally Stone, dairy pioneer Kingi Smiler and Underwater

World founder the late Kelly Tarlton.

A civil engineer, Sir Paul has involved his company, Carrus, in creating residential land subdivisions in Wellington, Palmerston North, Taupō, Rotorua, Hamilton, Auckland and Tauranga. He has developed about 10,000 residential, commercial and industrial lots over the past 40 years.

In 2019 Sir Paul was made a knight in the Queen's Birthday Honours list for his services to philanthropy and the community.

The New Zealand Business Hall of Fame recognises and celebrates individuals who have made a significant contribution to the economic and social development of the country.

Each laureate has a story of enterprise, hard work and success, as well as having generously contributed to their communities. The awards also seek to hold them as role models for young entrepreneurs.

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