

eVision August 2022

—
Parents of Vision Impaired
New Zealand Inc
supported by Blind Low
Vision New Zealand
(formerly The Blind Foundation)



pvi.org.nz
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Right: Children's beach toys are spread out over the sand.

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CHAIR REPORT JUNE 2022

KIA ORA E HOA MĀ,

So far this year there has been a lot of activity behind the scenes. My sincere thanks to Rebekah, who just gets on with the job representing and advocating for our organisation. It can be challenging working alongside other organisations that don't appear to be on the same page but the need to be collaborative to reach a positive outcome of change is the goal. Getting our PVI name out there in the central government space is a great credit to her work.

It is with regret that one of our newest board members, Kay, has had to tender her resignation from the Board due to her health. We wish Kay all the best and hope she is looking after herself and sending positive thoughts. I enjoyed her enthusiasm and fresh perspective and only hope she is able to re-join us again in the future. We now have a vacancy to fill and would be good if the Board could give this some thought. Ideally would have parents to approach as to their interest in preparation for our AGM in Dunedin. On a positive note, Rebekah and I completed the interview process for the parent support worker position and no doubt Rebekah will share more details with us on the new member to the PVI team at our June meeting.

I must comment on the excellent eVision and update publications. We have received positive feedback from the CEO of BLVNZ on this quality work. It is a key part of our work, as set out in our Strategic Plan, to reach out and keep parents informed and feel included. For this to happen, we do need to ensure parents actually know about us! It is clear that there are some road blocks for us to address and I would like to have some discussion around this at our meeting.

Lastly, I do hope you took the opportunity to give feedback on the BLVNZ Business Plan and completed the survey circulated back in May. We need to continually remind them of PVI's presence and the work we do.

**Kia kite wawe koe,
Judith**



Above: Krystal and Tim fundraising for Blind Low Vision Guide Dog Puppy appeal. **Right:** Two boys reading and drawing on a story book.



'Give them all of my dear love and a kiss. Tell them I think
long to wait before I see them at all
comfort in their affection at all
wait, we may all work, so far



PVI BOARD UPDATE



THE PVI BOARD MET IN QUEENSTOWN FOR THEIR JUNE FACE-TO-FACE MEETING.

We got through a fair amount of work on the Friday, which was just as well as snow closed the Queenstown airport on the Saturday, leaving pretty much all the PVI Board stranded! Thankfully Nick managed to leave before the Lindis Pass closed and get home to Twizel safely. Judith Hyslop was an absolute star and drove three hours through falling snow and over the ranges to deliver Rebekah, Justine, and Pascale to Dunedin airport, where they caught flights home.

Elizabeth and Cilla stayed another night in Queenstown where they were well fed by the stellar hotel staff. It was all very dramatic and not at all the carefully organised board meeting we had planned! The planned discussions on policy went out the window as we all had to make very quick decisions and scramble to sort transport before being completely snowed in.

**"IT WAS ALL
VERY DRAMATIC
AND NOT AT ALL
THE CAREFULLY
ORGANISED BOARD
MEETING WE HAD
PLANNED"**



Above: Rebekah and Judith getting in some local wine tasting ahead of our wine appreciation event at Conference! **Left:** Views on Friday were stunning!

NEW PVI STAFF MEMBER - KELLY FROM CANTERBURY

**HI, MY NAME IS KELLY WATSON,
AND I'M THE NEW PARENT
SUPPORT WORKER FOR
PARENTS OF VISION IMPAIRED
NEW ZEALAND (PVI).**



Above: Kelly Watson outside the Christchurch office of Blind Low Vision NZ.

I was born and raised in New Plymouth/Ngāmotu, before living in Nelson/Whakatū for 20 years, with my husband, and four kids. In December last year, we made the move further south to Christchurch/Ōtautahi, where we've all settled into life brilliantly.

This move is one, we ironically, we considered 15 years ago, when our eldest was diagnosed with retinoblastoma, a cancer of the retina, which saw her lose her right eye a week after diagnosis, followed by six months of chemo down here in Christchurch, where her specialist is based. The biggest shock came a few months post-diagnosis, getting genetic testing back to realise McKenzie had unilateral sporadic hereditary retinoblastoma, with a De novo gene (new mutation.) This brings more risk with age, and means McKenzie has a 50/50 chance of passing the gene on. We learned very early on to live by the motto to only worry if and when there is something to worry about.

We have four kids, aged 8-18, McKenzie (18), Lexi (15), Leo (10), and Dylan (8), who our youngest, is autistic, and attends a specialist school, I'm well aware of how complicated, scary, overwhelming, frustrating, and difficult our education and health systems can be for kids, who need that extra support for their everyday life. I've learned to advocate; I've encouraged others to do the same. I've learned 'no' is not always the final answer! But I've also learned when I've had to compromise. It's often a very fine line!

I linked with PVI about two years ago, when Lexi was diagnosed with idiopathic intracranial ocular hypertension. Whilst this doesn't affect her vision every day, she does go through stages where there are disturbances or imbalances in her vision. I have connected with other families who have themselves, or their kids have this condition. Both retinoblastoma, and IOH, are not that common, so can be hard to connect with families facing a similar situation. However, I still feel there are a lot of crossovers in emotions, frustrations, and joy with everyone's journeys.

"I THINK THROUGH ANY KIND OF DISABILITY ONE MAY HAVE, SELF-ACCEPTANCE IS A VERY IMPORTANT TOOL. THAT DOESN'T MEAN IT COMES NATURALLY, IT IS A PROCESS."

McKenzie hasn't let life stop her. It's not that I'd wish anything on our kids, but through her entire journey with her cancer, she had the right personality and attitude to deal with that, and that attitude continues to follow her through life now as an adult. She never fought the medical staff, she never argued about being put under anaesthetic, needles, any medical procedure. One thing I have learned is adults, could learn A LOT from our kids about facing the struggles life throws our way! I maintain, to this day, it was McKenzie who got us through that period of time. McKenzie is in the process of working towards getting her restricted licence and is employed working in the kitchen of a local rest home. Like a typical teenager, she works to have fun and spends half the day in bed at weekends! She is still deciding on what she wants to do post school, but I'm sure whatever she does, she'll do well.

The biggest support we have found, has been from other parents in the same boat as us, whether it's the same condition, or vision impairments in general. It's because we have found, our biggest pieces of information and knowledge has come from others who have been there, done that, and got the t-shirt!

McKenzie also loves to have some fun with her prosthetics. She's been known to place them in ice cubes, to spook her nana. If she is visiting, and wants a drink. If someone says, "it's all fun and games till someone loses an eye." you can guarantee McKenzie's next line is, "It's okay, I've got spares!" She also places her prosthetic on something when someone asks her to 'Keep an eye on it!" Her humour has allowed her to have total control and acceptance over what is just a part of her.

I think through any kind of disability one may have, self-acceptance is a very important tool. That doesn't mean it comes naturally, it is a process. It may even involve grief. For us there was because everyone knew McKenzie for her big brown eyes, and all of a sudden she was losing a part of what she was known for. I can remember about two years out, walking into a dental appointment for McKenzie, and the dental nurse said, "Oh my god, look at her big brown eyes!" I promptly burst into tears. I explained why I cried, and how much that meant to me. It was the first time in years, I'd heard someone say it. I think people became scared to mention anything. And it goes to show that, sometimes, that grief can still linger years later, and rise when you least expect it. Embrace it. Don't fear it. Work through it, it's all part of the story!

I'm looking forward to attending my first ever conference with PVI. I'm not sure what to expect, but I can't wait to build my knowledge base and connect with so many of our families!

Cheers, Kelly Watson

2022 NOTICE OF PVI AGM

THE 2022 ANNUAL GENERAL MEETING (AGM) FOR PARENTS OF VISION IMPAIRED NZ (PVI) HAS BEEN SCHEDULED FOR 10AM, SATURDAY, 18TH SEPTEMBER, 2022, AT THE DISTINCTION HOTEL, DUNEDIN.

Date 16-18 September 2022

Venue Distinction Hotel, Dunedin

Conference Fees and options

- PVI members: Full conference*: \$200/couple and \$150/single
- PVI members: Saturday day only (no accommodation required) \$30
- PVI members: Saturday day only AND Conference dinner \$50
- Non-PVI members and Organisation delegates: Conference \$250, Conference dinner \$50

PVI will pay for the following for members:

- Return air fares (within New Zealand), return airport transfers from Dunedin Airport to Distinction Hotel
- Accommodation (own room) at the Distinction Hotel Friday and Saturday night. This includes breakfast Saturday and Sunday morning.
- All other costs are parents' own.

*The full conference package includes Friday afternoon session, Friday meet and greet (dinner at delegates own cost), full conference day Saturday (lunch provided), conference dinner Saturday night, and AGM Sunday morning. We do ask that all PVI member delegates attend the AGM.

AGM documents, including the resume's for each nominated Board member are now available on our website: pvi.org.nz/documents/agm-and-board-nominations/

If you haven't registered yet, please go to and fill in the Conference Registration Form - docs.google.com/formsd/1bU1z29cztaoWt3XgiXflbGfsAXyul_zkAnq8W-1o-3g/edit

BOARD POSITION	NOMINATION RECEIVED
Tangata Whenua	Justine Edwards (incumbent)
Upper North Island	Raewyn Holland
Central North Island	No nominations received
Anywhere in New Zealand	Nick Mackay (incumbent)
Upper South Island	Elizabeth Manson (incumbent)



Above: The Distinction Hotel, Dunedin.

PVI POSITION STATEMENTS



AT THE JUNE BOARD MEETING, THE PVI BOARD RATIFIED THE FOLLOWING POSITION STATEMENTS. THESE ARE AVAILABLE ON OUR WEBSITE IN FULL – SEE [PVI.ORG.NZ/DOCUMENTS](https://pvi.org.nz/documents)

PVI POSITION STATEMENT ON EDUCATION

We support the right of all blind, deafblind, low vision, and vision-impaired children to have a fully inclusive education.

A child's right to an inclusive education is enshrined in New Zealand law and in the UN Conventions that New Zealand is a signatory to, specifically the following:

Article 23 of the UN Convention on the Rights of the Child (UNCRC) which recognises the special needs of mentally and physically disabled children, and which enshrines the right of disabled children to effective access to education. Article 23 of the UNCRC makes it clear that children and young people with disabilities should:

- be able to join in with activities, and their disability shouldn't stop them from taking part
- be able to join in and feel included at school get special care if they need it
- be able to choose what they do and have a say in choices about their lives.

Left: Teacher talks to group of children sitting on pillows on the ground.

Article 24 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) which recognises that disabled people have the right to an education, without discrimination and with equal opportunities. Additionally, the New Zealand governments stated approach to disabled learners includes the following legislation:

- The New Zealand Bill of Rights Act (1990) which states that everyone has the right to be free from discrimination from government and state officials, including state schools, and including on the grounds of disability.
- The Education and Training Act (2020) which requires schools to be inclusive of and cater for students with differing needs, including both disability and health conditions
- The right to an inclusive education and full and equal participation is reinforced by the New Zealand Disability Strategy.

Therefore in our position statement we expect schools, boards, staff, and communities to take sufficient steps to act in a manner that is consistent with the principles and rights outlined above. See our full position statement here: pvi.org.nz/wp-content/uploads/PVI-position-statement-education.docx

PVI POSITION STATEMENT ON BRAILLE

We support the RNZFB Boards position statement on braille. Link: blindlowvision.org.nz/about-us/position-statements/

In particular, the PVI Board values braille for supporting literacy and numeracy for children who are blind or low vision.

The PVI Board states that:

- People who are blind, deafblind, low vision or vision-impaired need to have the choice to:
 - develop braille competency
 - access convenient and affordable equipment for reading and writing braille and have access in braille to information that is available to the sighted public in electronic and print formats
- Students and learners who use braille as their primary literacy medium need to have curriculum material in braille

Access to braille skills development, braille reading and writing tools and materials is a fundamental right of all children and adults who are blind or low vision or whose vision is insufficient to allow them to use print effectively. The development of braille skills is particularly important for blind or have low vision children, as braille is a foundational key to literacy and numeracy that is essential for maximising participation in education and all other aspects of life. Download our full statement here: pvi.org.nz/wp-content/uploads/Braille-draft.docx

Right: A visually impaired pupil revises the maps.



UPCOMING THEATRE SHOWS WITH TOUCH TOURS

AUCKLAND THEATRE COMPANY AND PACIFIC UNDERGROUND

16 August - 3 September
ASB Waterfront Theatre

Audio-described performance -
Tuesday 30 August 7pm

Dawn Raids by Oscar Kightley revisits a shameful period in the 1970s when the New Zealand government cracked down on overstayers in Aotearoa.

In the wake of the apology, Auckland Theatre Company and Pacific Underground join forces to present, with Pasifika warmth and wit, a searing tale of injustice. A story revived and a large-scale work setting the space for *talanoa* and healing.

Audio-described performances are open to all and include a live audio commentary relayed to blind and low-vision patrons in the audience via an earpiece. Patrons with accessibility tickets can also attend a touch-tour 90 minutes before the performance.

For tickets go to www.atc.co.nz/auckland-theatre-company/2022/dawn-raids/

TIM BRAY THEATRE COMPANY PRESENTS *THE WHALE RIDER*, BY WITI IHIMAERA

24 Sep - 12 Nov
The PumpHouse Theatre & Māngere Arts Centre

Audio Described + Touch Tour -
The PumpHouse Theatre
Tue 27 Sep 1pm and Sat 15 Oct 1pm.
Touch Tour at 12pm

Māngere Arts Centre
Wed 9 Nov 10:30am
Touch Tour at 9:30am

Sat 12 Nov 1pm
Touch Tour at 12pm

Sensory Relaxed
The PumpHouse Theatre
Mon 10 Oct 10:30am
Pres-show introduction at 10:15am

Adapted for the stage by Tim Bray.

Bringing Witi Ihimaera's classic story *The Whale Rider* back to the stage in a children's theatre show unmatched. This beautifully rich story of *whānau* and *tikanga* is masterfully translated into a live performance that will absorb the viewer, from start to end. A poignant tale of forging paths and self-belief, this is the show all children need to see.

Created for those aged 5-10 years.
Show Run Time: 50 minutes.

For tickets go to timbray.org.nz/the-whale-rider/

Top Right: Two Pasifika women and two Pasifika men stand together closely as a family, in the lounge of a 1970s house. *Photo credit:* Ross Brown. **Bottom Right:** Māori woman on stage singing, and holding two small whale sculptures



STATE OF CARING REPORT 2022



CARERS NZ HAS RECENTLY RELEASED THEIR STATE OF CARING REPORT FOR 2022.

Right: Diagram illustrating the feedback from carers collected from surveys by Carers NZ.

You can download the full report here: carers.net.nz/state-caring-report/

1,648 carers completed the surveys. By making time to complete these surveys, Carers NZ has built a nationwide picture about how family/whānau/aiga carers are faring. It's a concerning picture. We know that many of you have not had breaks from your caring role for at least six months. You are getting through the pandemic, but without enough respite or help.

After viewing the survey responses, Carers NZ wrote to Ministers Carmel Sepuloni and Andrew Little to suggest steps they and the Ministry of Health and District Health Boards could take to sustain you through the pandemic. Carers NZ have had a positive response and are waiting to hear what actions will be taken to support carers in the months ahead.

We lost all essential support / carers / school and routines.

Safety, e.g. mask wearing and whether carers are vaccinated, is an ongoing problem. We need more consistent policy.

There is very limited support, especially for mental health

If only we could turn back time, to when breaks were possible.



At times we had no one to provide respite because of the lockdowns.

I cannot afford to pay my bills and struggle financially.

The job of a carer is massive. I didn't realise till I became one. It's exhausting.

GIANA'S HALBERG GAMES EXPERIENCE

PARTICIPATION IN THE HALBERG GAMES



Left: Giana standing in the discus arena, in the concrete throwing circle. In her right hand is the discus, and she is getting ready to throw. In her left hand is a red and white plastic hand clapper.

Right: Giana is getting ready to aim her bow and arrow in archery. Katie is assisting from behind and there are officials standing by them. There are buildings, trees, and people in the background.



Hi, my name is Giana Edwards and I am going to talk to you about the Halberg Games.

The Halberg Games is a national sports event for visually and physically impaired people between the ages of 8-21 years old. It includes sports like swimming, athletics, archery, running and throwing.

In 2021 I joined the Halberg games for the first time and competed between 23-25 April. All sorts of people from all over the country came to compete. I did so in swimming, running, discus, shotput, club throw and archery. I trained in term one of 2021 on a Thursday for athletics, then on a Sunday for swimming and on a Saturday for archery.

My good friend Katie helped support me as my guide.

I competed in the Halberg Games because I needed some blind sports to compete in, to help me with my fitness and health. In my own opinion, the Halberg Games are amazing for young physically and visually impaired people. It made me feel amazing doing archery, and I felt good about myself when I was swimming and it made me feel like a very capable person when I did athletics.

For the first time ever, doing the Halberg Games made me feel like my peers.

I would like to take a moment to thank the Halberg Games, the people who made this event happen, the people who helped and supported me with my training and all the people who competed.

- Giana Edwards



Above: Giana (with red and yellow ribbon in her hair) and one of the Halberg volunteers, in the pool competing in a Halberg Games swimming competition.

GIANA'S HALBERG GAMES EXPERIENCE

WATCHING GIANA PARTICIPATE IN THE HALBERG GAMES IN 2021 WAS SUCH AN AMAZING EXPERIENCE.

I remember signing her up, filling out the registration thinking, "Nah, she can't do this or maybe that might be a bit too difficult." I stuck to what I knew she had been practising. However, Cathy, our Parafed coordinator, said, "Sign Giana up for as much as you can. If she doesn't do them then that's okay, it's all about giving things a go." I reluctantly did this as I was unsure how things would pan out.

Fast forward to the first day and the opening celebration left me in awe. Seeing Giana and her Waikato team walk into the building where the opening ceremony was held with the biggest smile made my eyes tear up. She was equal, she was a part of something for her. Our first event was swimming. I had signed Giana up for the 50m freestyle, back stroke and flutter board, then all three again in the 100m events. Oh my gosh, who was I kidding? Giana in a pool she had never stepped foot in, a pool she couldn't even touch the bottom nor could her friend and guide Katie. The anxiety Giana showed clenching on to Katie then to myself because she didn't know which way to get into the pool was crazy, it felt like everyone was staring at us, like we were holding up the race. But guess what? No one minded. The looks weren't judging us, they were supportive and cheering Giana on.

Giana finally got into the pool and finished her first race, the proudness I felt in my heart was immense. Tears streamed down my face as everyone cheered for Giana and supported us through this moment. This was such an amazing moment and one of the highlights of the games for me as a parent. Giana swam three races with Katie then we decided to stop there as she was over it. We looked at other events, Giana had a turn on the rowers, then we went for dinner with everyone, Giana chatted to a few people. The next day we had athletics, (shotput, discus, and club throw) Giana did an awesome job participating in these event then it was on to running, Giana and Katie were awesome (running has been such a hard concept to teach Giana with her being totally blind) finishing yet again to a huge crowd cheering them on. Giana's face had the biggest smile and you could see both her and Katie were so proud of each other. Giana also participated in blind cricket, archery, and gymnastics alongside Katie as well.

Overall the whole experience of the Halberg Games was amazing, the parents, the children, the supporters, and organisers were so inclusive, supportive, motivating and patient. It was so lovely to be a part of something that I know Giana truly enjoyed and we cannot wait to go again this year, knowing there are other sports that Giana can have a go at including taekwondo, blind football and boccia. Giana has been training all year with her running, discus, and her shotput so I am excited to see what she will accomplish this time round. For any parents who are on the fence about attending, honestly come, join in, if you sign your child up to something and they don't want to do it on the day, that is totally fine, the whole experience is such an awesome thing to be a part of. Come and give it a try. The *kai* is the best, the accommodation is awesome and caters to wheelchairs as well. It's all accessible and the children will love it.

Right: A selfie of Justine, Giana and Katie.

- Justine Edwards



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Right: Multicoloured pencils are lined up on a piece of paper.

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