



PVINZ

eVISION NEWSLETTER

Welcome
to eVision
Newsletter
#106

Parents of Vision
Impaired New Zealand Inc
*Supported by the Blind
Foundation*



PVI.ORG.NZ



FACEBOOK.COM/PVINZ

We also have a private group for the parents.

WHAT'S YOUR STORY?

STORIES TO TELL SECOND EDITION

Back in 2013 we secured funding from the Ministry of Social Development's Think Differently campaign to produce *Stories to Tell* which I guess went to the core of PVINZ. At the time we had a launch at parliament with Minister Tariana Turia, and also staged a jazz concert and made a CD. Two of the musicians, Caitlin Smith and Mark Lockett, are vision impaired. Caitlin is a successful jazz singer and singing tutor in Auckland and Mark is now in New York City earning his keep as a jazz drummer!

We produced two reprints of this booklet because it was so well received. We have now been encouraged to produce a second edition!

What we need are your stories about a topic or subject or an experience that you have encountered as a parent or grandparent or sibling of a child or young adult who is vision impaired! The story should be one or two pages.

TOPICS THAT COME TO MIND:

- That diagnosis!
- The smallest progress is often huge in our experience?
- The light bulb goes off! I have found another parent or family.
- The question of a road block at your chosen school?
- The best teaching aide ever?
- Learning to be an advocate!
- After an awful prognosis suddenly you are achieving milestones you never thought possible?
- I taught my son to ride a tandem at 23, and our world together changed!
- Challenging bureaucracy?
- Are we the only parents of a special needs kid at this school?
- Special Olympics, Paralympics?
- Kick Start and beyond?
- Time out big time!
- Restless legs syndrome, what's that?
- Supporting other parents.
- Transition, a word that plays an important part in our journey!
- Twelve people at an IEP meeting, you are bloody joking!
- Supporting each other is important.
- Sleep, yeah right!

Just get your thinking caps on and pen a page or two and send it to me, David Heather david@pvi.org.nz

We want to have it done and dusted in two months!



STORIES TO TELL: FROM SHADOW PONY TO INTERCITY BUS

You will remember Laura riding Shadow and that was her means of transport.

Now it's the Intercity bus and the Hamilton Orbiter.

Last year Laura went to Hamilton to do a hospitality course at Wintec. This was a 20 week course. She lived in apartment type accommodation in Hamilton with four others run by Wintec. These are secure units with key passes so people can't just arrive when they want to.

This was new to her as she had to learn to cook and clean up and live with others. A bit of a test at first because three other students thought they could have 90% of the fridge space. Laura and a lovely lady from Te Kuiti could have the other 10%. Linda soon sorted that out for her. She thrived in this environment.

We would take her over to Matamata 30km away and put her on the Intercity bus and off she would go to Hamilton and then walk to her accommodation.

To get to Wintec meant a bus ride on public transport to the Rotokauri campus at the north end of Hamilton and a bus home again at night. She did have taxi chits but only used them once. I said if it was dark when she left Wintec she was to use them, but no. Stubborn. Wonder where she gets that from?

BLENNZ and the Blind Foundation helped in the transition to this new part of her life.

We went to France last year and it was great to see this young adult just cruise off shopping by herself and meet us back at a certain point. So relaxed and confident.

This year it's flatting in Hamilton and doing a vet nursing course. She is flatting, as my mate Joe on the PVI board said, "At the most furthest point she could get from Rotakawa campus. She is living at the south end of Hamilton and the campus on north end of Hamilton."

Once again we get her to Matamata then she gets the Intercity bus to Hamilton and another bus and then a small walk to get home. Once again no taxis.

Buses get her to Wintec and back. She is thriving at the course and her independent living.

We are very proud of our daughter Laura and wish to thank everybody who has had a hand in helping her.

*Remember people our children can achieve.
Give them space and do not set any limitations.*

Don and Linda.



MY STORY: MARIA FROM BRAILLE DESIGN NZ

I have always enjoyed helping people. When I was only 18 years old I use to visit retirement villages and used to bring along board games and music. Some of them didn't have visitors for months so they always looked forward to my weekly visits. It was lovely to see them smile while I was there.

I live in Taupo now, I previously lived in Auckland for 12 years. But it was time for a lifestyle change for me and my family and we love it here.

I have a son called Sebastian who is about to turn five and Annabelle who is two. They are both amazing kids, I have always liked the sound of 'belle' in a name and guess what? It's perfect for my daughter because she's *bella, or beautiful!*

I strongly believe now that things happen for a reason.

When Annabelle was born she taught me so much. There is nothing that will ever stop her, she is the most determined girl I've ever met. She knows what pain is but even through this she still gets up and carries on with life. A true example of strength.

Annabelle has had more than 20 surgeries on her eyes. When we thought things were about to stabilise she developed an infection in her left eye that took all the vision from that eye.

Because of her condition I decided that I wanted to do something from home as I always wanted to be available for her hospital appointments and surgeries.

I started sewing children clothes, and thinking of kids with vision impairment I decided to create 3D printed clothing labels. After doing a bit of research I tried to create other items like educational resources for children. I went to the Blind Foundation in Auckland to present what I had produced and they were really keen as they saw an opportunity to have new resources that they were either never able to access or found too expensive to purchase from overseas.

The more I realised there is not a lot of resources in braille the more I wanted to create. I have so far produced a New Zealand map, a world map, and alphabet cubes to name just a few. I love the idea that I'm able to offer new and interesting

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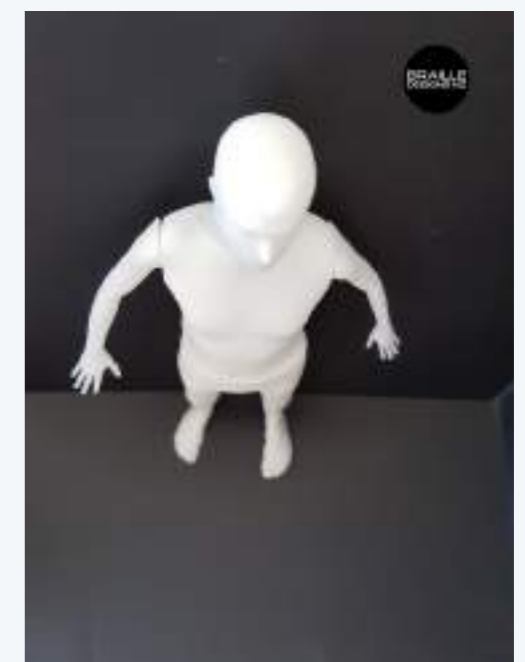
resources to the blind or vision impaired. I have had special requests from customers such as creating a human body as a puzzle for children with vision impairment and animal based 3D books.

The reality is that I can create almost anything. It has probably taken about six months of trial and error to fine tune my products.

I was also approached by a special needs school in Auckland and since then I have created a few more resources to show other schools.

Anything that I have done can be modified, adjusted and printed in different colours. Anything that I haven't done but you would like to see, contact me (brailledesignsnz@gmail.com) because there is a high chance that I can actually do it, challenge me!

I also create material custom bags to store the resources. I'm really looking forward to meeting new parents at the conference, listen to their stories and show them what I do. I will be taking a few sets of some of the resources with me.





THINK DIFFERENTLY: CHANGING ATTITUDES & BEHAVIOUR TOWARDS DISABLED PEOPLE

During 2012 our parent group PVINZ Inc applied to the Office of Disability Issues for funding to conduct a disability awareness campaign. This is part of the campaign that has been centered on Thorndon, Wellington. The heart and vitality of any parents support network revolves about the exchange of experiences, challenges, successes and failures with our disabled children.

The network and support experiences are unique. Parents and families proceed on their journey with their children. Parents are neither heroes nor cowards, but ordinary men and woman who try to face the reality of their child's disability with determination and courage, we all remember well the shock we experienced upon learning of our child's disability most of us new nothing about disability.

Suddenly we were challenged big time. In an instant we were expected to absorb and make decisions. To begin the journey- we begin to ask questions, to search for information about disabled kids. Confusion and frustration were common feelings

as we were advised by the medical profession, educators, social workers, rehabilitation specialist, friends and others to treat the child like any other child.

Much of the advice failed to address specifically the day to day realities of caring for our new arrivals, emotionally or physically. No one told us that we might experience a period of grief as a result of not having the perfect child. No one told us that this might be a lingering experience for many- or indeed never go away. We started on that rollercoaster of emotion that many of our closest friends and relatives could not understand.

Some of us felt such emotion and fear, grief, sadness and a loss of self-esteem and confidence. While most of our parents do discover ways to cope, sometimes we have been afraid to be honest about our feelings, worried about what professionals might think. We each in our own way need time to acknowledge, accept and understand our child's visual impairment.

In some cases it may take years before a realistic definition of a child's condition, treatment and future prospects, is understood, especially when the child has complex needs and several disabilities. From this background emerged our parent support network.

We found other parents and families and the sharing began. We suddenly had an instant engagement with another mother or father, who knew instantly our emotions, our predicament or our space. We found families who had solutions to problems we agonised over, we found families who could advocate who could climb the odd bureaucratic mountain, beat down the professional 'security door'.

We were back on the road. What seemed an obstacle or an emotional barrier could be challenged or coped with. Many of these exchanges and experiences could not or did not occur with our closest friends or relatives! They occurred sometimes instantaneously between parents and families who found

themselves with common emotions and challenges—there is a chemistry between parents!

Like any other community we have all had our successes, our failures, our gate keepers, and our power brokers. We have had our heroes also and many of these people are still there assisting our kids find their way in the world. We will have numbers of people available to talk with interested groups about the impact blindness has had on their life, on the experiences at school and university, at the employment market, and the medical community.

STORIES TO TELL: HON TARIANA TURIA CO-LEADER OF THE MĀORI PARTY



My parliamentary colleague: Paul Gibson our disability commissioner; Riripeti Paine, the chair of Parents of Vision Impaired; Paul Manning, your executive officer; family; friends and *tamariki/mokopuna*.

'Once upon a time' are magical words that have captivated our children and given joy to both storyteller and listener forever and a day.

Stories transport us to another time and place, on foreign shores or just around the corner. These stories grow in our heart and sit deep inside, waiting for the right moment, when like a little mouse peeking out from the corner, they are ready to face the world.

Today we are here to celebrate the stories that have been coaxed from the mouths of parents.

This project, Stories to Tell, represents the experiences from an organisation which encompasses over two thousand parents of blind or vision impaired children.

The project received support under the Think Differently campaign—one of the initiatives I am really proud of—an initiative which is driven by the challenge to promote

positive perceptions of, and greater social awareness towards, disabled people.

In the 2013 budget it was pleasing to be able to announce a further \$6 dollars invested into the Think Differently campaign.

And tonight, this event, represents all the promise and the possibility of that campaign. It reminds us of all the reasons why we need to tackle negative attitudes head on, to confront behaviours that limit opportunities.

One of the authors, Lee Rutene, gives voice to the aspiration that so many stories share: "In the future I want to own my house and control my own life. My advice for people like me is to be strong and do the best that you can, with what you have got, and don't let anyone tell you different."

This collection of stories starts, then, from that basis, and shares memories, and experiences that have shaped journeys both as parents and children.

The book provide glimpses into the lives of the everyday heroes who, in their own words, "try to face the reality of their child's disability with determination and courage".

proud parents wear. At one stage Christine and Nigel were told to prepare for his funeral. Hospital was the home away from home: appointments with orthopaedics, neurosurgery, ENT, hearing tests, eye tests, paediatricians.

But through it all Josh has continued to battle to stay here—and likewise his parents battle to give him the best that life can provide. He thrives in their cuddles, he bursts into laughter at a drop of a hat.

They say that laughter is the best medicine. And that is surely a common theme woven throughout all the tales.

Nico's tale is a particular ripper. He's enraptured with all the little things that any 10-year-old boy shares—the sound of a good fart, rolling a ball into the washing machine just to hear the hollow bang. And it's in the uncanny ability that a blind child has to spot a McDonalds sign from two miles away. As his parents say, "McDonalds, helping the blind see since 1940" should become their corporate logo.

One of the most effective messages in the book, is that relayed to us by our proud MC for the night David, and his wife Rhonda Heather. Their story contrasts what they were told, and what has instead been the lesson of their life.

They were told "this kid has no hope, you don't have to take him home he won't live past 3 years".

The purpose of a storyteller is not to tell you how to think, but to give you questions to think upon. And so we ponder, what might have happened if parents chose to believe the predictions of those with supposed authority? What might have happened to their child, to their family?

David and Rhonda chose, instead, to live by the 'Yes We Can' philosophy of life—their son learned to ride a bike at 23; he has completed the Otago Rail Trail twice on a tandem and has attended Outward Bound three times.

In other words, their family has done everything possible to turn the impossible into the everyday; and to fully embrace the challenges, successes and failures and important lessons in life.

When it comes down to it, perhaps that's one of the greatest impacts of this project, Stories to Tell. Of course, throughout the stories are written many moments of frustration and confusion; days of despair and nights of anguish.

But as Kirsty Ferguson says in her memories, there is so much more.

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There are plenty of giggles to share; and in every case the children exceed the expectations that all others have put upon them—that is except those closest and dearest to them who want nothing more for their children than the entire world.

And so it is in the words of the children, that I want to leave us tonight. Who better to honour the courage, the faith, the trust and the all enduring spirit of optimism that tell the stories of the parents of Vision Impaired?

The parents in this booklet – like so many parents of disabled children—are fiercely focused on what people can do, rather than what they can't. They are indeed the champions of the philosophy our government is advancing in the Enabling Good Lives approach.

And so, the last word goes to Kirsty, who sums up a message which could be and should be heard by every parent in this book:

“So to you, our mum and dad, we say thanks for the gift, the love and the journey.

And whilst the journey wasn't as you'd probably hoped and dreamed for, you have climbed Mount Everest and further, not only for Richard, but through your drive and determination for the disability world.

Not an easy road, but one we wouldn't have any other way; we have your fighting spirit and we thank you for your strength and role models. Here here to fighting spirits and interesting journeys”.

I want to thank you all for the privilege of being able to say, “I now declare Stories to Tell officially launched.”

Parents of Vision Impaired New Zealand, Project Thorndon
Hon Tariana Turia, Co-leader of the Māori Party
Monday 10 June 2013; 5pm; Grand Hall, Parliament Buildings





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