



Stories to Tell

Stories to tell

Following a meeting in Thorndon with the Office and Disability Issues, we were challenged to submit a creative proposal to run a disability awareness campaign! What followed was the sort of “left field” idea that we stage a campaign around where we were sitting in Molesworth Street. We were after all at the epicentre of where all the action happened! From there the ideas were stirred and boiled and a proposal was submitted for consideration.

The Office of Disability Issues approved our proposal for funding with enthusiasm, and we thank Trish Green and Josi Wilson for their support and encouragement. Parent support networks in many ways survive on stories. Parents of disabled kids face a very steep learning curve and the story telling provides us all with new knowledge, new confidence and more importantly new friendships. The good, the bad and the ugly stories are all important.

Throughout the lifetime of PVINZ we have had the ongoing support of the Royal New Zealand Foundation of the Blind. That support both financial and advisory has meant we have been able to concentrate our energies on parents, families and children. This has allowed us to advocate widely.

The support of the wider “Blind Sector” has to be experienced. We are diverse in view and style, as in any family. We are without doubt supportive and very strong.

We have in conjunction with this campaign a planned Jazz concert at Old St Paul’s Church in Thorndon and we are indebted to Mark Lockett and Caitlin Smith for making this possible. They have also recorded a compilation CD to celebrate the “Stories to Tell” campaign.

To the parents, families, friends who have contributed to our stories we say thank you.



When one door of happiness closes, another opens; but often we look so long at the closed door that we do not see the one which has been opened for us.



Helen Keller

Stories to tell



Parents of Vision Impaired New Zealand Inc

The idea of "Stories to Tell" evolved from the Office of Disability Issues: Think Differently----Changing attitudes and 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 make 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!

For those of us who had families in the late 1960-1970s, Thorndon was the head quarter for the

Wellington Branch the Royal New Zealand Foundation of the Blind.

That was the start of many of our connections and networks. As I recall there were two social workers in operation Audrey McEwen and Harry Wilkinson.

There was at the Tinakori Road building a rose garden which became the focal point of the children's Christmas parties where friendships and connections started. The parties and the presents from Father Christmas were all paid for by the "Mayor of Thorndon".

Our selection of Thorndon was influenced by some of these long standing connections. In addition some of our siblings are now working and living in the district,

some children are attending school, our dedicated teachers and teacher aides are in the area. We are still part of this very compact and diverse suburb.

However, many of our stories have never been told, and we think they should.

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.

Our successes to date have been:

- We have in collaboration with the blind sector and the Ministry of Education a new model of education service delivery that is now operational in New Zealand. The Blind and Low Vision Education network NZ is an outstanding model of blindness education...the NZ model is truly cutting edge and world class.
- We have been closely associated with the introduction of the (unpaid) Carers Strategy
- A petition to parliament to increase the number of specialist teachers to work with our children. Outcome: 30 new specialist Resource Teachers Vision plus a new rebuild of the Homai school campus.
- The development of a national regional network of support parents
- Our annual conferences and Annual Meetings. These are supported well by our parent community
- The bi-monthly production of "Vision" our parent magazine, some 1250 magazines sent to families nationwide every two months.
- A web site www.pvi.org.nz
- Employment of paid staff that has taken us from a parent volunteer model to a more professional/social model of support for parents.
- Continued financial support from the Royal New Zealand Foundation of the Blind for the past 25 years.
- A journey: - from emotions to advocacy and support....

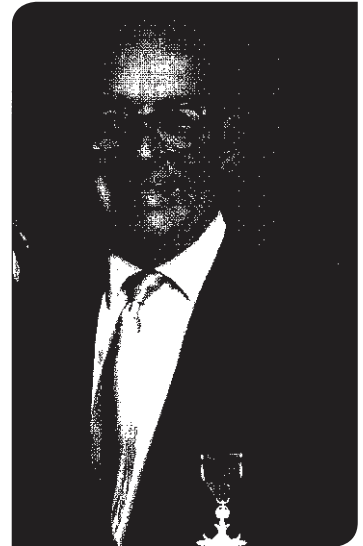
The realisation that this support for our children is a life long commitment. That along the way we need to stop and smell the roses, energise and to re-learn and focus on what our children can achieve as society is continually reminding us of what they cannot....

Being humble of life and its ups and downs...knowing that we will cope...in time

Stories to tell

History of the Mayor of Thorndon Blind Kiddies Appeal and the Henderson Trust Fund (Based on the memoirs of CW "Bill" Henderson)

The Mayor of Thorndon Blind Kiddies Appeal had its beginnings in a mock mayoral race in 1941 in the Railway Hotel. Bill Henderson had stopped for a beer at the Railway hotel and watched the process of electing a "Mayor" of Thorndon. At that time Thorndon was a workers district, with wool stores, tramways, watersiders and railway workers. Bill remembered a few years earlier when he had been blinded by an accident with an emery wheel for 11 months. He had always thought that if he ever got his sight back, he would do something for the blind. Now here was an opportunity, and the next year the race for the Mayor of Thorndon was a penny a vote. Two candidates stood that first year, and Ernie Heaphy was crowned Mayor of Thorndon outside the pub on 22 November 1941. 26 pounds had been raised, all in pennies of course. The following year three candidates raised 45 pounds, and the first public crowning ceremony took place. By this time Thorndon looked forward to the contest and lots of people wanted to stand. 1943 saw 97 pounds raised and the need for a solicitor to administer the growing fund. Solicitors, Geo Mellish, Les Rose and currently Alistar Macalister have seen the Mayor of Thorndon grow and move into the Henderson Trust fund. But it was the contests over the years that have been memorable. It moved all over Wellington, each candidate having a hotel as headquarters. They needed to sort out areas of fundraising, which covered the Hutt Valley, City areas and north to Porirua. The contest ran for 5 weeks and a huge number of candidates, commit-tees, trustees and collectors were involved. After the contest, a five-day "rat catcher" contest was held to cover the refreshments and expenses of the crowning day. The winning "rat-catcher" received a large rat trap, cheese, helmet and rubber hammer. Counting the votes was a major exercise involving bank officers and police. Wooden and later metal collection boxes were opened and pennies galore were counted. Imagine the year that the bank officers didn't turn up and 8000 pounds of public money was guarded overnight by a nervous Bill Henderson and his sons. The crowning of the Mayor of Thorndon was always a special event. Parades, clowns, and a variety of bands livened the festivities. Many dignitaries attended over the years including MPs, Local councillors and Mayors and Governors General. Mayoral robes including the hat and chain of office and the cup that list the winning hotels are kept by the Foundation for the Blind in memory of the many workers of the Mayor of Thorndon. 1985 was the last year the contest was run and Bill Henderson passed away in 1986. But the legacy of his dream and the work of count-less people over the years lives on in the Henderson Trust Fund. Trustees administer the fund and grants are made to children across the Wellington region.



Bill Henderson

MR. HENDERSON RECEIVED M.B.E. IN 1962 FOR SERVICES TO THE BLIND

Bill O'Reilly

In a recently published book, Pauline O'Reilly Leverton talks about her father Bill O'Reilly as the Mayor of Thorndon:

"The election was one with a difference, where people voted with pennies, and everyone could vote as many times as they liked. Money raised was donated to sight-impaired Wellingtonians. Of the £5,393 raised in 1955, more than half was in votes for O'Reilly, one of five local candidates."

"It's quite amazing he was chosen considering it was still a strong anti-communist climate. He was a warm and likeable guy. He was described as 'truly loved' at his funeral, and that language wasn't used a lot in those days 1955."

The book Commo Bill: 'People's Poet' was 19 years in the making. The book is a mix of history, biography and anecdote. "It started out geared for academia but Dad would want it so other people could read it too."

Excerpt from "The Mayor of Thorndon", Bill O'Reilly, 1948

Thorndon's the most democratic place in this fair and favoured land,

For here a bloke can cast his vote with a handle in his hand,

It doesn't matter who you are, you may come from anywhere,

From Timbuctoo or Oamaru and help us elect our Mayor,

For we don't stand on ceremony, we're not the exacting sort,

And there's never a mayoral candidate who isn't a thorough sport,

So you will not find us mean enough to limit your votes to one,

For every vote you register like the rays of a friendly sun

Will warm the hearts of all blind kids who dwell in Wellington...

PAULINE O'Reilly Leverton's father Bill O'Reilly died when she was 12. Pauline set about collecting every piece of information she could find about her dad, a prominent member of the Communist Party New Zealand and national secretary of the unemployed workers movement. Only there wasn't much to find.

"I looked in left wing publications to glimpse Dad's name, but it was almost never there. When he died a lot of cards and telegrams arrived. One said, 'When the history of the working class is written down, Bill O'Reilly will have an honoured name', but that hadn't happened," says Leverton.

So she decided to write a book about him.

"I wanted my children and grandchildren to know that he was a brave man who fought for people's rights."

Stories to tell

A fathers perspective

A timeline

Day 1:

Lights flickering, alarms going off and white coats huddled around an incubator all working furiously. Inside was my daughter, Jessica, born 3 months' premature weighing 800 grams. Jessica's condition very fragile not expected to live, mother is still unconscious....

I have my other 3 children with me; I am in Auckland away from home and away from my supports. Inwardly I am panicking, I am scared beyond anything I have experienced before, yet I must remain strong for Jessica, for my other girls.

Day 2:

Marie my wife finally awakes, she had an allergic reaction to morphine, she is going to be okay... we arrange to have Jessica baptised on advice from the doctors... God's will was done... yeah right! I was angry I was in shock. What I was not aware of was God was looking after me, at times I believe we were carried and looking back I do not know how we did survive such trauma.

Day 60:

Jessica was still with us, she is a fighter. All sorts of drama's she has endured and she is still battling on and slowly gaining weight.

She had now reached the magical 5lb and able to be transferred to P.Nth hospital nearer our home in Levin. But perhaps more importantly we have been able to hold her, this has been so beneficial to both Jessica and Mum and Dad. Jessica is our fourth daughter.

We leave National Women's in Auckland; we are bringing Jessica to a hospital nearer home...

Day 90:

Easter weekend 1987 Jessica is allowed to come home, finally we are all together, it has been a roller coaster ride from hell or so I thought; it sadly gets worse.

6 months:

Jessica still has very fragile health, this is her norm. Marie and I are very, very tired. The phone never stops, we have continual appointments at home, our place is no longer our own, our identity has gone, we are known as Jessica's parents.

8 years:

Jessica has recently undergone her fourth stomach surgery to get her stoma working correctly, she has undergone two brain surgery operations, numerous admissions to hospital. Her health is fragile to say the least. Both Marie and I now know how to play the system to get the best for Jessica and us. Our girls are developing a sense of social justice as they see how hard it is for Jessica and her family. James is born so Jessica has a brother.

26 years:

Jessica is living away from home and has gained some valuable independence skills.

Her school years were fraught with Mum and Dad, mainly Dad keeping the schools and the Ministry of Education honest. Funding to meet her needs;

Jessica's mainstreaming experience was not a good one... no friends, she knew she was different so she herself sought the company of other disabled children.

Left school and entered the adult world... Jessica was poorly transitioned, parents had to re-learn a new government funding process, still trying to keep up!

Looking back, today, and the future:

It has not been easy. What has kept Marie and I sane is the support from other parents and wine!

We joined Parents of Vision Impaired NZ due to Jessica's sight loss condition of ocular albinism. We became actively involved with PVINZ as this organisation focuses on the parents like no other we knew of. To us, we needed to hear from other parents, we needed to try and make the world better for other parents, to this day this still rings true... it is the "knowing" and sharing that is so important.

Where to from here, lord knows but we are ready, Jessica is strong and we have learnt so much from her; some may say we too have been reborn!

Paul Manning

Husband to Marie, Proud Father of 6



Keep your face to the sun and you will never see the shadows.



Helen Keller

Stories to tell

It's the little things.

Having a child with a disability opens your eyes to things that we would otherwise ignore or take for granted.

With 10 year olds it is all about TV, play stations or Xbox. Who is the best super hero, if there is still such a thing? The latest toy, the way you wear your cap and the type of scooter you have.

Nicholas (Nico) loves company, someone to share in his fun. His fun is rolling a ball down steps, or into a washing machine to get the hollow bang it makes, a trip to the super market is met with the same amount of excitement as if you said we were going to Disneyland.

Standing at the letterbox, watching the car head lights at dusk and listening to the evening bird song. A walk making sure to bang only the letter boxes that make a good noise, once met with anger from a grumpy owner now met with a smile, and still apologies from a red faced mum or dad.

To know to walk past a dairy with dad because dad has a sweet tooth and always buys lollies, even if when he did not eat all his breakfast.

Waiting at the gate for dad to come around the corner with the mower, is like waiting for the ice cream truck to arrive.

A drive in the car, and the uncanny ability for a blind child to spot a McDonalds sign from 2 miles away, "McDonalds.....helping the blind see since 1940" should be there corporate logo.

A hydro slide is the best thing in the world, and the climb up 5 flights of stairs 35 times is a good work out for a weary mum or dad, who can barely walk the next day.

The sound of a good fart, his or someone else's, a sneeze or burp always is met with a laugh.

All of these things we bypass as routine, they barely get another thought in your day, but it is these things that make the difference, keep your sanity and in some ways make up for the tough times we have all had, and we have had more than our share.

We seldom look at the future, the future is tomorrow or the next day, looking further on is not worth the grief. We will deal with that when we need too. Focus on now, the kids, your wife your marriage.

With so much to get you down you need to stop and look at the little things.....

Like when he goes to bed!!!!

A Story To Tell

by Nancy Paviour-Smith (mother of Jann Rutherford)

Many Wellington people have read or know of Jann Rutherford's academic and musical achievements, but how did it all become a career?

Jann started attending Samuel Marsden College for her secondary education with support from the Kelburn Visual Resource Centre staff. A few terms later, after settling in, she found that quite a few of the girls had holiday employment and she wanted to find a job for herself.

After careful thought and planning a Braille list was compiled of all the phone numbers of suitable Wellington restaurants. Jann was very good on the phone and already proficient and accurate with phone numbers. She diligently worked her way through the list and although she had a few interviews initially none resulted in employment.

After one phone call she was granted an interview with Bevan at Great Expectations Restaurant in Ghuznee Street, she was finally successful and employed to play their piano while customers enjoyed her music with their meals. Jann continued working there for quite some time while still at school and Polytech.

As a result of this employment one of Jann's most successful compositions was created and called "Expectations" after her experiences there.

"Expectations" was recorded on her first solo album "Discovery" in 1998.

This success led to more employment in other venues and restaurants as she gained qualifications firstly at Marsden and then at Wellington Polytechnical School of Music, as it was known then.

Jann was very fortunate with the skills and dedication of the music tutors she had at Marsden, Polytech and privately.

This is only one of many interesting and inspiring stories in Jann's short life and I suppose the moral to this story is that, "Everyone deserves that first chance, because you never know where and what it might lead to."

With love from Mum

Stories to tell

Jazz pianist, composer

1964-2003

Jann Rutherford, the jazz pianist, composer, teacher and poet who was a prominent and unique musical force in Australia and New Zealand, died of cancer at the age of 38.

Her fight with the cancer diagnosed on her tongue and lymph gland was the final chapter in a life studded with a bravery that bordered on heroism, although Rutherford herself would have been quick to dismiss such an assertion. Blind from birth, she pursued the zero-security, artistically high-risk career of the jazz musician, moved by herself from

New Zealand to Sydney to further this career, eked out a living and confronted her cancer and its treatment with typical optimism and courage.

Born in Dunedin, New Zealand, in 1964, Rutherford began learning the piano when three years old after she had been attracted by the sound of her neighbour's instrument. In 1977 she was awarded the Sir Denis and Lady Blundell (Governor-General) Homai College prize "for showing outstanding determination", and continued her extensive studies of classical music until 1984.

The next year she gained a diploma in Executant Music from Wellington Polytechnic, majoring in jazz, and her career path was established. She began performing regularly in that city, and recorded for radio and TV.

Her move to Sydney in 1989 would have been a daring step for any young jazz musician trying to make it on a bigger stage; to do it alone and sightless was remarkable. She attended the Sydney Conservatorium, where she gained an associate diploma in jazz studies (with Mike Nock and Roger Frampton among her teachers) and an associate diploma in music teaching. In 1993 this array of qualifications was augmented by the Licentiate Trinity College, London.

Meanwhile, Rutherford had made an impact on the Australian jazz scene. She worked with the singer Kate Swadling and fellow New Zealand (and blind) pianist Julian Lee. In 1990 she entered the National Jazz Awards at the prestigious Wangaratta Jazz Festival, and was runner-up a result she duplicated the following year. She won the competition in 1993, when she was also nominated for a Mo Award.

Rutherford led several bands, including a trio with the leading bassist, Craig Scott, and the doyen of Australian jazz drummers, Alan Turnbull, and she enjoyed a lengthy collaboration with the versatile saxophonist Paul Cutlan. In 1999 she recorded an outstanding album of solo piano called *Discovery* (Tall Poppies).



Jann Rutherford at The Basement. Photo copyright Joe Glayshe



Jann Rutherford playing at Strawberry Hills Hotel. Pic: Joe Glaysher

This revealed many of her strengths as both a pianist and composer: the beauty of her touch and choice of voicings; a flair for releasing tension (both musically and in the listener) and for resolutions; a deeply intuitive understanding of the use of space; a narrative sense to bind her improvisations into extended coherent statements.

Her music eschewed any aggression, even shying from anything overly robust in favour of an exquisite delicacy, beautifully exemplified by the title track, *Discovery*. If soft watercolours predominated over bright oils, nonetheless her music often carried a

buoyant and infectious optimism, as on *Expectations* from that same album.

"I just love jazz," she told the *Herald*. "I like the sound of the piano and the fact that you can do so many things with it." As Mike Nock observed in the liner notes to *Discovery*, "Jann Rutherford is a wonderful pianist ... [who] explores many moods in which her beautiful sound, sensitive ear for harmonic nuance and warm expressiveness are heard to full advantage." Rutherford also worked with the singer Christa Hughes, accompanying her in the successful cabaret *Beer Drinking Woman*, which was spiced up by the pianist's witty asides and quips. She sang in the stunning Martenitsa Choir, worked for the Royal Blind Society, wrote poetry, and collaborated with the composer Romano Crivici (from *Electra String Quartet*), on a presentation at the Powerhouse Museum called *Sounding The Museum*, which allowed people to experience the facility through hearing rather than sight.

Diagnosed in May 2002, her cancer required intensive radiotherapy. After six weeks of this she made a super-human effort to fulfil a concert commitment at the Side-On Cafe in late June, leaving barely a dry eye in house when she dedicated the performance of *Expectations* to herself.

A final testament to her considerable gifts came with the album *The Scented Garden*, on which her quartet gave scintillating renditions of 10 Rutherford compositions. It was released posthumously.

John Shand

First published in the Sydney Morning Herald 19/3/2003

“Love is like a beautiful flower which I may not touch, but whose fragrance makes the garden a place of delight just the same.”

Helen Keller

Stories to tell

Trust!

I've been in this job for a long time working for the RNZFB (Royal New Zealand Foundation of the Blind) as a Social Worker/Counsellor. I'm one of the most privileged people there are....as I get to work with trust.

When I meet a family....or a young visually impaired or blind person.....my job is to facilitate an environment where concerns can be shared and "pain" can be heard.....where plans can be made....decisions can be "reflected upon"....where "future" is not a word you need to be scared of but can be exciting.....

Over those many years I have felt enriched by the insight and knowledge of parents, by their courage to not "hide" but face reality and fight the next battle.

I tell all parents....."all the professionals walking through your life are "service providers"they are not in charge of your child..... you are.....therefor you are in charge".

When I attend IEP's..(Individual Education Plans).....I may not say much (I am not the educational expert)....but my guaranteed question to parents at the end of the meeting always is "do you feel you have been heard"? If they feel they haven't.....we start again!

Over the years the joy in my work has come from getting to know families and young people with vision loss.....from observing their courage and determination... that vision loss nor any disability can't define who you are or want to be.....and my rewards have come from the trust given to me and opportunity of "walking the road together". I feel humbled.

One day I walked into this young family to do a needs assessment. Their child was a little girl with huge complex needs.....physical, intellectual...and visual.

When I sat down with mum she told me that the day before the therapist from the hospital had been and had told her honestly that she didn't know what to do with this beautiful little girl. Mum smiled a sad smile and it made me feel sad to. Here was a family who so loved their little girl and understood very well the limitations placed on her....and on them as a family....but wanted to have hope in a realistic way.....and wanted a future for their child completely understanding the struggle around that. The message they were given was one of no hope.

I suggested we visit Conductive Education in Lower Hutt... where they do amazing work with complex needs children and the Conductor in charge has amazing skills and patience in achieving. They agreed to come...and we visited.

The Conductor was very welcoming.....in his approach already giving a message of hope! He then put the little girl in a walker so her feet could touch the ground.....and slowly he helped her to become aware of her environment and of what she could do to move herself a little bit.....and she got it. And when she got it.....she smiled.....and the mother cried.....as this was the first time she had seen her little girl smile. Her words to me at that moment "it is so amazing to see the identity of my daughter come through...this makes me so happy...."

Quite a few years ago now I visited this family who had given birth to a little girl with a severe eye condition. At the time the girl was 2 months old. I discussed with the family the support out there for their child and also how the vision loss of their little girl affected them. They were down to earth parents who were prepared to walk the road with their child.....and so they did. Over the next 20 years I was involved from time to time, either when situations went wrong..... or people did not work well with the parents.....and with the young girl herself when she grew up....."checking things out while having a coffee".

One day I was invited to the IEP (Individual education plan) at the College she was attending. There were lots of suggestions and ideas of how this girl could and should do better or different.....with the focus very much on her visual limitations. There was nothing wrong with that and some suggestions were very good.

I noticed how the mother every time made sure her daughter had the opportunity to speak and give her opinion..which was not always the same as the professionals opinion. But the message the daughter was giving the professionals was "trust me that I know myself and know where I am going and how to do that". And the mother wanted the professionals to hear that and supported her daughter.

The "little" girl is now 21.....very successful.....not without struggles though. Her vision has decreased even more and has left her with very little vision. But it has not stopped her from achieving or setting a path for herself to follow. And as from the start...the parents have been there valuing and supporting their daughter. They have never allowed her to be defined by her disability but have always insisted she be defined by her knowledge and skills.



Be of good cheer. Do not think of today's failures, but of the success that may come tomorrow. You have set yourselves a difficult task, but you will succeed if you persevere; and you will find a joy in overcoming obstacles. Remember, no effort that we make to attain something beautiful is ever lost.



Helen Keller

Choices and Expectations

The youngest of three girls, I was born in the late 1950s and grew up in Manurewa where my family had lived for three generations. What made my family life and upbringing slightly different from my neighbours was that I had blind parents whose values, ambitions and expectations for me were the same as they had for my sisters. Reading braille, seeing my father go to work and my mother cook and keep house were all things my family took for granted. So becoming a blind parent was no big deal in my family's eyes but it was a big deal for people not as familiar with blindness as my family was.

It was thought slightly controversial having children as a blind person whose genetic eye condition had a 50/50 chance of being passed on to my children. But adoption was not an option as in the late 70s it was still thought that being a blind mother would significantly disadvantage any child I may adopt. I was determined to prove the authorities wrong; after all, my own parents had given my sisters and me a good upbringing.

I had three children who all inherited my cataracts and glaucoma resulting in varying degrees of sight loss.

For the first few years of being a mother, I battled with health and education professionals often having to justify my ability to be a good practical and capable mother. This made me more determined than ever to be a good role model for other blind parents by taking every opportunity to educate other blind parents and professionals that it is ok to be blind and that my children would receive similar opportunities to other children their age.

I crossed the boundaries of perceived sensibleness imposed on me by others, and began to study when my youngest daughter was nine months old and I was 30. Ten years later I graduated with a Masters degree in Sociology. I attributed this thirst for knowledge to my oldest daughter who has a learning impairment.

I often would discuss with the children comments I had received from the public, educators and health professionals. Hopefully they would learn from my experience as a blind mother that sometimes you have to prove yourself to become respected by professionals. This we did and my children and I became well respected by our local community, school and health professionals.

Raising teenagers was challenging, rewarding and sometimes disappointing. However, we all survived. I had to discuss options, be realistic about what they could not do and what they could do and use my own experience. To have a good wholesome life you need to create it by being honest, open, brutal and realistic about your individual situation... For example:

My oldest daughter was 19 when we moved cities and she chose to remain in the city she had grown up in her friends and supports. She attended a special unit attached to a high school and as an adult she needs support with day to day living tasks. Eleven years later she is living alone with support; she works part-time in a laundry. She is happy walking to and from work knowing that exercise is good for her health.

My son the middle child, had to realise driving was out of the question for him. He attended boy scouts since he was six. The scouting movement offered him good solid friendships in a passion for the outdoors in a good social setting for him which he found difficult to find at school. I had expectations he would be academic and go to tertiary education; however he chose not to and has taken a very practical life. After leaving school he

became involved with the Association of Blind Citizens at a local level and established some good friendships with other blind people. Now he is married, and has a child. He lives in a small provincial town working full time in a supermarket. I had to let him do what he wanted in order for him to find himself and lead a life that he finds satisfying and rewarding. Now he is leading the scout troop and giving youngsters the same opportunity he was given in the great outdoors.

My youngest daughter has had a different life to the others as she is able to drive and managed to find a job while still at school. Like her brother she worked in a supermarket for nearly nine years before going on maternity leave. But like her mother she is adventurous and capable and has had several overseas trips to the US, Europe and the UK all of which she has planned herself.

As for me, well I just carried on being their mother. I raised them on my own since my youngest daughter was seven. They saw how I could enrich their lives with lots of good conversations, scouts and guide camps, a chance to participate in local school activities and know and understand those people around them who meant so much even though I could not easily afford to take them to ballet lessons or Saturday sports. The most influential person who they went to for advice was a very special neighbour, my widowed blind uncle who happened to live over our back fence.

I gave them one of the richest gifts I could, which cost me nothing. That was the art of being articulate, express their thoughts, talk about their dreams and plan what they would like to do. Now they are ambitious in their own ways, they are responsible and liked members of their communities.

I see in them what I tried to do for them as a blind mother. That is the ability to ask questions, never be told something is impossible and being realistic about what they can and cannot do because of their impaired vision. Having impaired vision is always different for everyone so it can't be wrapped in paper and tied with string. No one can say that the experience of blindness is the same for everyone. As my grandmother always said, "I tell you what I think, I just ask that you listen to what I have to say and remember what I've told you. You are free to make your own decisions providing you are responsible for your actions." Good advice for any parent.

“My friends have made the story of my life. In a thousand ways they have turned my limitations into beautiful privileges.”

Helen Keller

Stories to tell

Yes we can!

They said: At St Helens maternity hospital in 1971 after two weeks, this kid has no hope, he is a vegetable and you don't have to take him home!

We said: No thanks we'll take him home! Wow he's some vegetable.

They said: At paediatrics we don't think he will live past 30 years!

We say: Well he's still here and going great guns!

They said: At the International Ophthalmologist's Conference in Wellington in 1972. We think the surgeon should embark on cataract surgery immediately! He did!

We said: That changed our son's life having what was revolutionary surgery at three months!

They said: He should talk by the age of six.

We said: Okay we believe you but he never did talk!

They said: He would never walk and have reasonable mobility.

We said: Really! He learned to ride a bike at 23. He has completed the Otago Rail Trail twice on a tandem.

They said: If you don't send your son to the deaf blind boarding school at five your marriage will break up!

We said: Forty four years later we are still here together!

They said: He would have great difficulty with attending Outward Bound at Anakiwa.

We said: Oh really! He has attended Outward Bound three times and we suspect he would like to live there!

They said: Your son will have to return home from his schooling because of his erratic behaviour

We said: Oh really, why?

They said: At the hospital he has quite severe "kerataconis of the eye". He needs to have a cornea transplant and we assess his chances of getting his sight back at about 25%.

We said: Go for it! And it was 100% success factor made possible by the wizardry and skill of the surgeons and staff at Wellington Eye Ward.

They said: As his residential service provider we will expel him from his home if you continue advocating for him.

We said: We will advocate for the rights of the disabled.

They said: He's expelled, and he was!

We said: We won! He now has the service he deserved.

They said: He is unemployable!

We said: Anything is possible, and he has that little job. And where else but Thorndon!

David & Rhonda Heather

Joshua

Our lives changed 11 years ago when young Joshua was obviously keen to make an entrance into the world and into our family – he arrived early, born at 28 weeks gestation, 12 weeks early, weighing 1.1 kilo, yes, just over 2 blocks of butter, he was as long as my lower arm, his little feet were not much bigger than my wedding ring!

He arrived into this world, fighting for his life; we had him baptised that night, called both sets of grandparents to the hospital (from Upper Hutt and Masterton) we were in Wellington hospital. I always remember a nurse saying to me weeks later, the babies that are baptised are the ones that survive.

We were in Wellington hospital for 6 weeks and once Josh stabilised, we were transferred out to Hutt Hospital, our base hospital, we were there for 8 weeks, in total Josh was in hospital for 100 days, not a number you can forget! We had to do the car seat test before we were allowed to go home, Josh had to cope with being in a baby capsule for a few hours, we nearly blew it but just scraped through, yay, we were going home, just after our wedding anniversary, which was a best gift to us.

Not long after Josh's birth he suffered brain bleeds, unfortunately he had 3 of them, and this did the damage to our wee lad. The prognosis was not great, we were told the worst case scenario, and at one stage we were told to plan his funeral, we hadn't even had the chance to celebrate his arrival.

Josh came home on oxygen, we had cylinders in his bedroom, tubing around the house, we didn't go far without his monitor, in fact we did one trip to Levin and the battery went flat on the way home, we were beside ourselves with this, but in a way it was the beginning of weaning us off the machine – that was the way we were, Josh was ready to be weaned of things, but it took us a little longer!!

Josh started to have infantile spasms before he turned one, I remember being told if he didn't get them before he turned one, we might be able to escape them, but at 11 months he started having them. Today at 11 years of age, Josh has been free of seizures (touch wood) for 27 months!! WOOHOO.

At the age of one we took Josh to Conductive Education, it is a Hungarian physiotherapy program, and I'm sure without this, he wouldn't be as mobile as he is (he can walk, but with aides, and he is an extremely fast crawler, especially when it's his turn on his iPad!). As Josh did really well at Conductive, we decided that we would send him to the Conductive Education unit at the primary school in Naenae. He was there for a couple of years and mobility wise, he was doing really well.

At the age of 7 we made the decision to transfer him to Kimi Ora School in Thorndon, this was a huge decision for us, and one that we have never looked back on. It meant a longer taxi ride for him, but he loved the drive in and out of the city, and I worked just down the road from him, so was able to pop in during my lunch hours ☺ Eventually Kimi Ora got the go head to build a new base school in Naenae and satellite unit at Evans Bay Intermediate, so back to Naenae we went. The new school is lovely, light, airy, new equipment, therapists on the school ground, no waiting months to be seen by a speech therapist, etc, he receives this every week at school now, and what a difference it has made for him and for us. Josh is non verbal so he was very frustrated at not getting his feelings, wants or needs across to us – he has learnt the PECs system (Picture Exchange Communication), basic makaton sign which has helped him so much.

Stories to tell

During Josh's life, especially in the first few years, we spent many hours at hospital, overnight stays, surgeries, seizures, routine appointments – orthopaedics, neurosurgery, ENT, hearing tests, eye tests and paediatrician, it seemed every week we had a hospital appointment, as the months and years went by, the visits became less frequent and now most of his hospital clinics are either 6 monthly or annually.

Josh has cortical vision impairment, we don't know what he sees out of his left eye, his vision out of his right eye is not so bad, but with cortical vision impairment, it can come and go, what vision he has we feel he uses it very well, sometimes you forget that he has a vision impairment, you get used to Josh looking at things on an angle, everything to look at is brought up to the right eye, when he watches TV, his head is turned to the right, I'm not sure he even knows he has a left eye... Josh's main disability is cerebral palsy, but we don't see him like that, he is our little boy, he fought a hard battle to stay here and we will always battle to get him the things he needs to live his life in a manner that is good for him.

Josh is a loving child, who loves nothing more than to have rough and tumble play with his dad and cuddles with his mum. When he was little, he didn't have any idea who his parents were, now he most definitely does, if we pop into school to see him, he is really excited to see us.

Josh has his grandparents, aunties and uncles, and cousins who all love him dearly, sadly out of his relatives, only one set of grandparents live close to us, the rest of his extended family are in Nelson, Wairarapa, Auckland and Brisbane. We have holidays with his cousins and he gets very excited when he sees them. He relates in different ways to everyone he knows, there is some little thing that he associates with each person; this is pretty cool to watch the interaction between them.

We belong to the PVI, Blind Foundation, Blennz and he has a vision resource teacher who sees him at school. He used to wear glasses when he was little, but we had one heck of a job trying to keep them on him, we tried all sorts, and hoped that he would realise he could see better with them on – some days he wore them for ages, other days, it was a real issue just to keep them on.

Josh has brought so much to our lives, he has the most wicked sense of humour, he loves the Wiggles, enjoys watching Hot Seat Millionaire and bursts into laughter at a drop of a hat. Josh does swimming lessons and this has helped with his confidence around water, he loves it, especially the hot pools 😊.

The story of the trip to Holland comes to mind, we love our Holland, and wouldn't change it for the world.

Christine & Nigel Pask

Very proud parents



Alone we can do so little; together we can do so much.



Helen Keller

The book of Life

A mothers love like the book of life
Is shared by those who are willing.
Written with neither beginning nor end.
Bound with courage and strength.
Chapters drawn of life's experiences.
Pages full of knowledge and wisdom.
Paragraphs overflowing with dreams and aspirations.
Lines like the beauty of age as it glistens.
Sentences giving meaning to feelings forlorn
Words that hold secrets once foretold.
Letters that watch as these journeys unfold.
Comer's that mark the time and the pace.
Spelling mistakes only you will erase.
The book of life is shared by those who are willing
It tells stories of love and life a worth living.

Below is a greeting to those who have shared a special part of Ngarangi's life but have since passed on. I love the words, it is also relevant as June marks the beginning of "Matariki" our Maori New year celebrations. What a lovely month to celebrate the Thorndon project

"Tirohia ake nga whetu
Me ko Matariki e arau ana
He tiki mai tahau I nga mahara e kahi nei
Whakarerea ake
Na te roimata koua riringi
He puna wai kai aku kamo"

*"As I look to the stars and the brilliance of Matariki
I remember loved ones who have returned home
My heart yearns for them
And I weep"*

This beautiful waiata was written by an ancestor of mine "Mihi ki te kapua" late 1800's she is a well-known composer of Ngai Tuhoe.

The English translation is my interpretation.

Riripeti Paine

Stories to tell

Its not a fairy tale - its our tale.

Our twin daughters were both born with inherited retinoblastoma. Our surviving daughter, Amanda, retains 6/36 vision in her remaining eye.

Initially the large amounts of support we required were provided by family, friends and professionals. Eventually we found the support of fellow parents, through Parents of Vision Impaired, who provided us with an in depth knowledge and empathy not able to be offered by others.

The guidance through various stages of life's transitions, offered from seemingly chance encounters, with parents who have had the same or similar experiences should not be under-estimated nor under-valued.

"The confidence my parents gained from this type of support has been instrumental in them allowing me to grow and develop - mainly without being wrapped in too much cotton wool!", explains Amanda. My life has been enhanced immensely by a similar level of support offered through camps, courses, and youth groups provided by the RNZFB.

And so through our tale the support continues to help smooth the rough times.....

“For, after all, every one who wishes to gain true knowledge must climb the Hill Difficulty alone, and since there is no royal road to the summit, I must zigzag it in my own way. I slip back many times, I fall, I stand still, I run against the edge of hidden obstacles, I lose my temper and find it again and keep it better, I trudge on, I gain a little, I feel encouraged, I get more eager and climb higher and begin to see the widening horizon. Every struggle is a victory. One more effort and I reach the luminous cloud, the blue depths of the sky, the uplands of my desire.”

Helen Keller, The Story of My Life

Welcome To Holland

Many of our parents read, enjoyed, and passed on a story titled “Welcome to Holland” that we all related to very closely. But first a little about the author:

“Welcome to Holland” is an essay, written in 1987 by Emily Perl Kingsley, about having a child with a disability. The piece is given by many organizations to new parents of children with special-needs. Emily Perl Kingsley is a writer who joined the *Sesame Street* team in 1970 and has been writing for the show ever since. Her son Jason Kingsley was born with Down Syndrome in 1974. Her experiences with Jason inspired her to include people with disabilities into the *Sesame Street* cast, including an actress who uses a wheelchair, Tarah Schaeffer, and even Jason himself. Jason’s story was the topic of an hour-long NBC television special in 1977, titled “This Is My Son,” and with co-author Mitchell Levitz, Jason wrote the book “Count Us In: Growing Up With Down Syndrome.”

In 1987 Kingsley wrote “Welcome to Holland,” a widely published and translated piece which compares the experience of raising a child with special needs with traveling to Holland. The same year a made for television movie she wrote “Kids Like These,” premiered on CBS-TV. The film, about a middle-aged couple who have a son with Down Syndrome, won numerous awards.

Welcome to Holland

Emily Perl Kingsley

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, “Welcome to Holland.”

“Holland?!?” you say. “What do you mean Holland?? I signed up for Italy! I’m supposed to be in Italy. All my life I’ve dreamed of going to Italy.”

But there’s been a change in the flight plan. They’ve landed in Holland and there you must stay. The important thing is that they haven’t taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It’s just a different place.

So you must go out and buy new guide books. And you must learn a whole new language.

Stories to tell

And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

Emily Pearl Kingsley was interviewed by Creative Parents Inc and we reprint extracts from that interview as they resonate with many of our experiences on this side of the world.

Why do you think "Welcome to Holland" has had such resonance, for so many people?

EPK- It's about a lost dream, any lost dream. Any change from the original plan. It says that it's okay to continue to feel the pain of the loss; that it's legitimate pain. It says that you're entitled to be disappointed -- which then allows you to go on and enjoy what you did get.

How did you come to write "Welcome to Holland?"

EPK- I was doing a lot of counseling of families with new babies born with Down syndrome. When our son Jason was born the obstetrician told us he would never walk or talk -- that we should institutionalize him and tell family and friends he'd died in childbirth. After we got the doctor's gloomy prognosis, we nevertheless decided to give it a try.

Jason turned out to be so different from what the doctor predicted that we determined to try to prevent other parents from believing doctors who were not up to date in the new treatment protocols for these babies. We wanted to urge other parents to give their babies an investment of some of their time and energy and see how it turned out - see for themselves,

not go blindly according to a doctor's obsolete information.

It was the fact that raising Jason turned out to be a special kind of reward and joy (not, perhaps what I had expected - but rewarding just the same) that I was inspired to come up with "Welcome To Holland. " I felt that if we could save just one family from being discouraged, from getting the kind of bleak prognosis we had, we would be doing a lot. Sitting by the bedside of a new mom I found that the words about Holland just came out of my mouth. Later I wrote them down. "Welcome to Holland" was part of the final scene of my movie, "Kids Like These." I'm not quite sure how it emerged into the larger world.

Were you surprised by the response to "Welcome to Holland?"

EPK- I was absolutely surprised. All sorts of things have developed out of the piece in the intervening years. Two people have set it to music. There were several conferences organized around "Holland." In one of these the decor started off in Italy (checkered table clothes, chianti bottles, etc.) When people came out of their workshops the decor had been changed to blue and white delft pattern with pots of tulips all over.

I get reprint requests every day. When one family got the prenatal diagnosis of Down syndrome, they said that Welcome to Holland had helped them adjust to the situation so well that they decided to name their child Holland Abigail if they had a girl and Holland Alexander if they had a boy. The father made tulip-design stained glass windows for the baby's room. They had a girl and I have the photo of Holland Abigail right here.

How have things changed over the years?

EPK- There have been enormous changes in the last 20 years. We now take it for granted that kids with Down syndrome will read. Jason started to read at age four. The prevalent attitude back then was that kids would be able to learn to zip a jacket and wipe a table.

Now there is often full-inclusion of some children with Down syndrome into classrooms with their non-disabled peers. Before, they were lucky to be in the same building. Many kids with Down syndrome are in regular classes. It doesn't work for everyone. You need to go on a child by child basis. Some do better in an inclusion setting -- some don't. Inclusion works best with an excellent support system. Where a school is willing to work to make it successful, it almost always is.

What would you like people to know about "kids like these?"

EPK- I'd like people to know that these are people with the same feelings, hopes and dreams as anybody else. They are individuals - with individual ideas, opinions, tastes and capabilities.

And a Follow Up:

Subject: Follow up to Welcome to Holland by Cathy Anthony, Parent Advocate

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I'd planned.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger - the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But, this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad. I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned.

Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Stories to tell

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest.

And, yes, Holland is slower paced than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and look closer at things, with a new appreciation for the remarkable beauty of Holland with its' tulips, windmills and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined!

(Cathy Anthony is a parent, advocate and presently the executive director of the Family Support Institute in Vancouver, BC)

“ I who am blind can give one hint to those who see: Use your eyes as if tomorrow you would be stricken blind. And the same method can be applied to the other senses. Hear the music of voices, the song of a bird, the mighty strains of an orchestra, as if you would be stricken deaf tomorrow. Touch each object as if tomorrow your tactile sense would fail. Smell the perfume of flowers, taste with relish each morsel, as if tomorrow you could never smell and taste again. make the most of every sense; glory in the beauty which the world in all the facets of pleasure reveals to you through the several means of contact which Nature provides. But of all the senses, I am sure that sight is the most delightful.”

Helen Keller

Looking Back

Educational Support in the Wellington Area for Students with Vision Impairment

In the 1970's a group of Wellington parents lobbied the Department of Education for the establishment of a Visual Resource Centre for the Wellington Education Board area. At that time all children with severe vision loss had to be educated at Homai College in Auckland – with the exception of a Visual Resource Centre in Christchurch. The children sent to Auckland, some from as young as 4 ½, boarded at the Royal New Zealand Foundation for the Blind (RNZFB) hostels at Homai and completed their education far away from home.

Thanks to this small, dedicated group of parents the Kelburn Visual Resource Centre was opened in 1978 with one teacher and a part-time teacher aide. A second teacher was employed towards the end of that year. At that time there was no formal training in New Zealand for teachers of the vision impaired. Collaboration between RNZFB and the New Zealand Education Department ensured that teachers at Visual Resource Centres were able to have professional development at Homai College, observing classroom teachers working with blind students.

The Wellington Braille Club (a dedicated group of volunteers) based at the Wellington Regional RNZFB in Tinakori Road, Thorndon provided Braille instruction to these teachers and the opportunity and encouragement that enabled them to complete the Braille Transcriber's Certificate. The Braille Club continued to support the teachers and students of Kelburn Visual Resource Centre by manually brailleing all reading materials for early braille learners and including secondary material in specialist braille codes for mathematics, science and music. Members of the braille club became the first teacher aides for blind students as they moved through to secondary schooling, not providing in-class support but producing day-to-day braille requirements such as handout materials, blackboard notes and examinations.

At different times all the schools in the Thorndon area have had students on the roll of the Visual Resource Centre.

In January 2005 Kelburn, along with all the other Visual Resource Centres around New Zealand and Homai College became BLENNZ, the Blind Low Vision Education Network NZ, a new national school for all learners with significant vision impairment.

Comment:

The support provided by the teachers, teacher aids and other teaching professionals in New Zealand to our families and children has been enormous and had an everlasting impact on our lives. BLENNZ, the Blind Low Vision Education Network NZ is a world class education service delivery model.

Stories to tell

An Ordinary Life

This is only a small taste of my life, my experiences, achievements. There's so much more I could say about the people who I've benefited from, the services at the Foundation that I've valued and continue to use. As well as other experiences I've had with friends and family, to name a few.

In terms of my education, being mainstreamed into schools in Wellington was the right thing for me as it provided me with the love, support and classic experiences of family life that I wouldn't have had if I'd been at Homai. I also really enjoyed the friendships I developed and skills I learnt at Brownies, Girl Guides and later on Youth for Christ. It's fair to say that some schools were a lot more experienced and accepting of having visually impaired students than the other schools I attended which made my time there a lot more enjoyable and easier. And the assistance I received from the Itinerant teachers from the Visual Resource Centre and teacher aides was excellent, along with the crucial training I had in touch typing and Braille which I've been able to use throughout my life.

My time at Victoria University was a great experience, being able to pace my studies and do 2 papers a trimester was a huge help in my achievements. I also tapped into the resources and support that the University provided such as note takers and volunteers to assist with the readings I had to do each week. Technology has played a large part too in my achievements at Victoria University with my introduction to Jaws, the screen reader programme which also helped with the readings for each paper. I've also used the screen reader in three administration positions in various organisations over the years, as well as my mobile phone.

I love travel having had the opportunity to travel with my family growing up. A couple of years ago I discovered a British based tour company that specialises in doing tours for visually impaired people, each person is assigned a sighted guide on the tour. I participated in a fabulous tour around Australia and am keen to do more in the future. On that tour I made friends with a Welsh woman who I'm meeting up with in Melbourne in a couple of weeks and we're going to spend 5 days there together which I'm really looking forward to. I've also travelled on my own to Hong Kong and stayed with my sister and her family there which was a wonderful experience.

Over the years I've been involved in various projects one of which was a Human Rights Commission enquiry into how to make public transport more accessible for people with disabilities. I also was on a committee while at Victoria University that focused on the facilities and buildings on the campus, where I assisted in improving the steps and lifts around the campus.

I do use a screen reader on my computer and on my mobile phone. Having the screen reader on my phone is a great tool as I can access Facebook and Radiosport websites.

Jenny Rickit

Memories

My first memories of being the sibling, take me back to times when I really didn't understand the ins and outs of a brother who was deaf, blind and what was termed in the day "retarded" was. I had no idea. Richard was my brother, we shared stuff, and we shared giggles but I wanted more.

We shared a bedroom, and I guess one day it came to me that my endless questions or comments to him in the darkness went largely unanswered. He was however nice to snuggle up to, when nightmares visited. I distinctly remember lecturing him one night about how "I know you can hear me.... And you're really upsetting mum and dad by pretending not to speak."

Little did I know that he never had a choice and being able to speak was going to be minimal in terms of the challenges that life faced him.

It was about the same time that I figured out he had this different apparatus on, (his hearing aide harness) which got him a bit of attention. So I decided I would like some attention too and made myself a makeshift hearing aide, my moulds being made from cotton wool, cello tape, string and felt tip to try make them cotton wool bits camouflaged. I have no doubt my parents will either deny this, but its memory is solid. The reason it's so clear is someone turned up to visit and I felt compelled to carry out new disability and my gear, and attempted to speak in deaf muted tones! How embarrassing!

Ridiculous looking back, but real at the time and I guess part of the processing of accepting and coming to grips with life with a brother who would never say my name, never laugh simultaneously with me or play a trick on me. No matter how many late night lectures I gave!

I also remember thinking how I felt mum and dad spent more time, more money, more everything on him and that this was grossly unfair. Mum and dad proceeded to spend time effort showing me monetary sums, that this in fact was the complete opposite.

Over the time growing up, Richard went through fads of things, and its funny how these fads become second nature and quite normal. They range from a variety of things and repeated themselves and we learnt later they were part of the disability Richard had. Some of the fads included smashing lightbulbs, balloons, women's tights, running away, smashing windows, running away (nakid) smelling dark headed women's hair, pink wafer biscuits, smashing windows again, running away and hospitals.

Despite the fads and the trials and tribulations Richards life bought us as a family, he never stopped growing and changing and learning himself as a person. Once we realised speech was out of the question, mum and dad were dedicated to teaching Richard sign language which has made his silent world become one in which he can now ask and communicate to the outside world. Something that was controversial but changed his life for the better. Sometimes you have to rock the boat to make progress.

Although Richards cognitive age was never going to reach Einstein status, it astounds me, and proves that learning is life long, no matter how young or old. It proves that those brain neurone connections can still connect even at 41. Thanks to the supports of his home and his daytime career (a fluent signer, deaf herself and a deaf

Stories to tell

teacher), Richard is signing better than he ever has in his life (I'm talking 2013) and is actually asking for things, making decisions about things which is something he has never done. A recent testament to this, is his new found desire to consume as many cheese rolls as possible, without burning his mouth at iride in Thorndon Quay, and giggle to himself about how clever he is at mastering the art of eating the treats provided! Without being told!! Something he would previously have waited patiently until he was "instructed to try more".

Richard was once termed as the modern day Helen Keller, deaf blind, mute and autistic, caused through Rubella contracted by our mum, unknown to her, in her early pregnancy. Preventable, even today with vaccinations and interestingly a growing disability in some islands countries not immunising their people.

Despite living in a world of silence and my parents being told at birth he was going to be a vegetable, never to walk, talk, run or speak, Richard has exceeded our expectations. He has accepted his own disability alongside the rigours of teenage-hood and hormones and come to a place in which he can function, hold down a job, enjoy life, ride a bike and has a giggle and a beer.

What we wouldn't give to show them, (the Doctors) how different he was to their initial predictions.

He has gone on to achieve great things. He's walked, he's run, he's swam, he's skied, he's baked, he's got a job, he's been to outward bound more times than he can count, he walked me down the aisle with Dad, he's learnt to ride a bike, he's laughed and lived. Not only has he grown, but I mustn't neglect the growth and support he's had along the way from our mum and dad. Not an easy task, a hard and never ending journey but one which was made so much more rich by their support and dogged determination.

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 Mt 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 it 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.

Kirsty Ferguson



Change: A bend in the road is not the end of the road...Unless you fail to make the turn.



Helen Keller

This is my story

I was born in 1975 in Wellington and I went to primary school in Wellington. It was good at school but I am not going to say too much on it.

I really enjoy the support of my family in whatever I did after my school years. I did a few maori courses then I enjoyed the Para Olympics where I did quite well as I have cerebral palsy.

The sports I did in the Para Olympics:

I competed in swimming 50 ,100 and 200m backstroke and 50 and 100m breaststroke I was new Zealand champion for my level of swimming. I was also in wheelchair rugby and basketball but my favourite was swimming.

These days I like to think I am a spokesman for people with disabilities speaking up for those people who have trouble communicating. I am on a few boards such as Wellington After Care Association. CCS Disability Action.

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 you can with what you have got and don't let anyone tell you different

In advocacy I am a volunteer for People's First and I also like public speaking especially to kids. That is what I like most a advocacy.

Lee Rutene

“The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart.”

Helen Keller

Stories to tell



Inquiries to purchase the CD can be made to our web site: www.pvi.org.nz

**Our favourite whakatauaki is from :
The Whale Rider by Witi Ihimaera**

*Kia hora te marino
Kia whakapapa pounamu te moana
Kia tere te karohirohi
I mua I to haerenga
Kia tau te rangimarie
May the calm be widespread
May the ocean glisten as greenstone
May the shimmer of light
Ever dance across your pathway
May you always find peace.*



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