

# eVISION NEWSLETTER

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Welcome to eVision Newsletter #101

Parents of Vision Impaired New Zealand Inc

Supported by the Blind Foundation



PVINZ



PVI.ORG.NZ



FACEBOOK.COM/PVINZ

*We also have a private group for the parents.*



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# EDITOR SPEAK

## WELCOME E VISION 101

We promised Paul Manning that we would write number Vision 101. We did that and it was in October 2014! So here we are after a lie down and a glass of milk and a cookie ready to re-create an electronic edition of our Vision Newsletter of old!

### **So what is the significance of 101?**

*My dictionary says:* It means "introductory something". The allusion is to a college course with the course code 101, which in the American system and probably others indicates an introductory course, often with no prerequisites. We are starting from scratch.

After over two years of consultation, discussion debate, anger, frustration we are finally seeing emerge the results of the Special Education Update circa 2014-2015. This was an extensive and exhausting consultation process at last started to challenge the effectiveness, accountability and transparency of the many millions of special education dollars that seem to race past our eyes and we missed the bus?

In term one a pilot programme will be conducted by the Ministry of Education in the Bay of Plenty region. Full details of Minister Parata's statement and the planned implementation are available on our web site or the Ministry of Education website.

So you can see we are back at Vision 101, but with a difference. While some will say there has been little achieved in the last twenty years, we would suggest that the world has changed significantly. BLENNZ did not exist in 1997! Some of the special education resources were not available then. More importantly attitudes have changed. Parents will continue to play a significant part in influencing the effectiveness and accountability of services, but only if they make a concerted effort to do so.

Telling our stories, and sharing our experiences as parents, siblings and children has been at the core of our newsletters of old. The current day costs and printing and postages have meant that we have had to look at the new technologies that are available.

This prototype is an experiment we are trialling in 2017 to connect with as many of our parents and whanau as possible. We will need your support to make it a success to

be able to reach you by email, by our website and Facebook. We do have a closed Facebook which now has 150 parents talking to each other, and we do want to extend the parents participating. The support and networking that has been achieved within that group has been astonishing.

We are also collecting and collating a new edition of Stories to Tell, and we would welcome your story or experience we can include.

In early November we gathered in Wellington for our annual conference, Transition with Success, and it was a success. The gathering included 75 parents from throughout New Zealand, of all ages and stages, some new, some conference veterans. We were joined by our friends and partners, the Blind Foundation, BLENNZ, Retina New Zealand, Deaf Blind Aotearoa and a number of our family. The MC and sheriff was Julie Woods, 'That Blind Woman' from Dunedin.

Our key note speakers were Jill Lane and Phil Wysocki from the Ministry of Health, Sally Jackson from the Ministry of Education, Dr Andrew Marshall and Erikka Helliwell from the CCDHB in Wellington.

We covered a wide range of issues and processes connected with transitioning our children and youth from early days and beyond the umbrella of school education. We listened, we networked, we laughed and as usual had the odd cry.

We must express our sincere thanks to the Blind Foundation for funding support to PVINZ Inc and of course the Vision Newsletter since little old number one. The ability to communicate with parents, family and the wider community has been critical to our organisation moving forward and growing the support we have received over numbers of years.

The sharing of stories and information has served us well in the past, and as we go electronic into outer space we have no doubt eVision Newsletter will do the job!

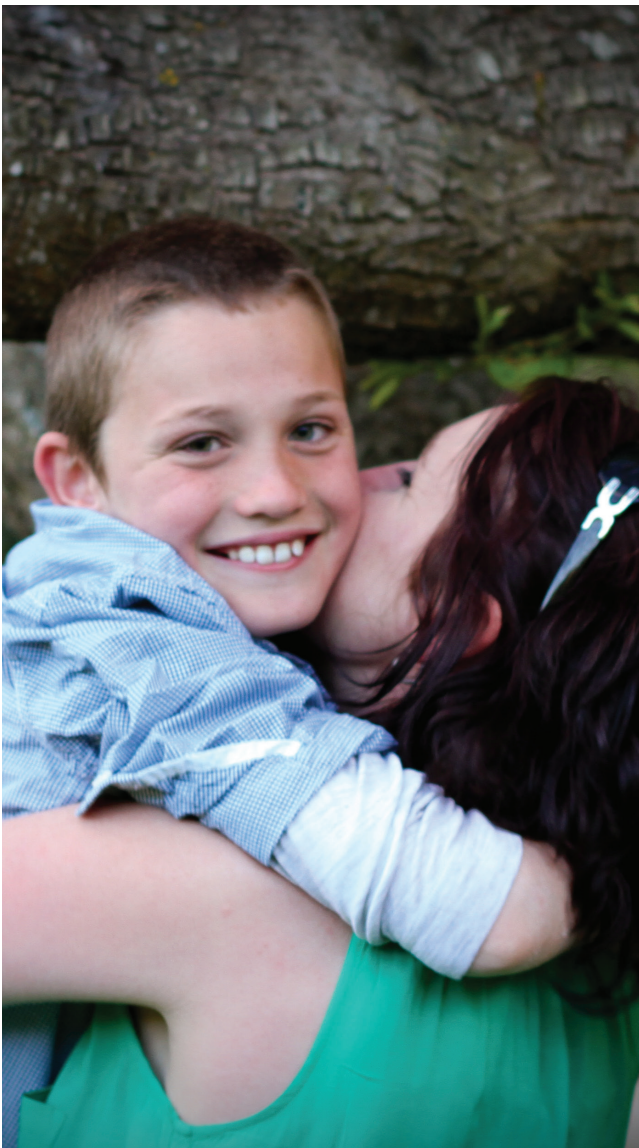
Your job now is to spread the word, send us your email addresses, and follow both our website and Facebook.

Enjoy the journey,

David Heather  
Executive Officer

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# E VISION NEWSLETTER LETTER TO THE EDITOR



Dear Editor,

So what's wrong with special bro'?

I am writing as a father of a special needs kid, who we always said was special and he goes to school where he has a special needs unit, a special needs teacher aide, lah de blah de blah and a special needs coordinator. Simple! My mates understand, my neighbours understand, the boys in the Golden Oldies Rugby XV understand, my mum and dad understand, even my brother understands. At last count most countries in the developed world understand. But now bro' new instructions have appeared out of the education cloud and we are told.

We are into Learners Support. The Ministry of Education have determined we need to eliminate the use of the words Special Education and replace WITH Learner Support.

*Changing the language used to describe the system. The use of the term "special needs" singles people out, and by concentrating on learner's deficits, can marginalise individuals and create a barrier to a fully inclusive education system. Further analysis of the implications of this change is required.*

I mean how stupid is stupid bro? My mates in the Golden Oldies Rugby XV have after 14 years just gotten their heads around Special and now a change. So what do I do now? Race around call young Johnny an LSK? (Learner Support Kid), refer to Miss Brown as our Learner Support Needs Coordinator?

As for me and the wife we will be known as LSPs, Learner Support Parents or LISPS for short? ... and then that becomes LITHP and we hit the politically correct stratosphere.

As you can imagine my mates in the Golden Oldies Rugby XV are naturally going to think I am involved in a revolutionary jock strap just invented by the International Rugby Board, add to that my explanation that I am now a LITHP! This is not happy news.

So they spend three years consulting and then decide the vocab is wrong?

As you can appreciate I have chosen to remain anonymous in case the Learner Support police cut our ORS Funding.

Sincerely,  
Special Needs Dad from Rural New Zild



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# E-VISION 101

Tena Koutou Katoa (Greetings)

There are many whakatauaiki (Proverbs) that are of importance to society.

**'E KORE AU E NGARO HE KAKANO AHAU I RUIA MAI I RANGIATEA'**

'I will never be lost for I am a seed sown in the spiritual realm descended by those before me'

This proverb has been handed down throughout generations, and exists as a reminder to us all of the special nature of each one of us. We are grown of the sacred seed - raised and nourished with a plan and purpose until we bloom into the beauty that becomes our reality. This planting, raising, nourishing and nurturing was never meant to be in isolation, it is and should remain the role of family, whanau and community.

The Kakano (seed) Parents of Vision Impaired NZ inc was planted several years ago as a way of nourishing and providing support for a community of people gifted with the joy of parenthood and today this community continues to thrive giving nourishment and support to others.

Our 'Vision' magazine is now 101 copies old and has become part of the heart of who we are. Over many years it has pencilled the thoughts and feelings of those who have chosen to contribute and now held as an archive of wealth, experience and also remembrance of those who have now passed.

Today a new kakano (seed) is sown, born of the reality of our time, for some of us older gardner's we may take longer to bloom. This seed will grow and become known as E-Vision, our wish is that all will contribute towards this growth, the knowledge harvested will be shared as a way of nourishing and nurturing well into the future.

On behalf of PVI Board members I thank all who have contributed to our Vision Magazine over many years as we welcome new beginnings.

Ma te atua koutou he manaaki (God bless)

By Riripeti Paine - Chair





# “E KORE AU E NGARO HE KAKANO AHAU I RUIA MAI I RANGIATEA”

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## ONE

Look what makes a garden grow upon this wondrous land  
We all began as seedlings scattered on the sands  
Within our spirit wonderland there lies a special place  
For we are born of greatness with purpose and with grace.

## TWO

Seeds begin to flourish from the heart of sacred springs  
Caressed within the wairua the soul of man it brings.

## THREE

Sheltered in the sanctity of our mother's womb  
Calling to the house of man, Te whare tangata blooms.

## FOUR

Your seed has been delivered upon this long white cloud  
Whenua now buried and covered with a shroud.

## FIVE

Aotearoa still yearning, for the seed that has been sown will blow across  
the universe to keep this garden known.

## SIX

From time to time, we will plant seeds, sometimes against the grain  
Today our faith has brought us here to sow new life again.

Sea of rippling waters - come bless this great campaign.





## CONGRATULATIONS MARY FISHER



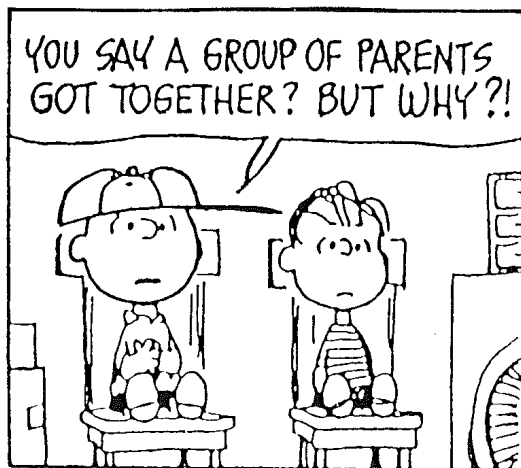
MARY WELL DONE!  
PARALYMPICS 2016 RIO GOLD MEDAL  
WINNER AND WORLD RECORD





# STORIES TO TELL SECOND EDITION IN PRODUCTION!

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We are also collecting and collating a new edition of Stories to Tell, and we would welcome your story or experience we can include.

We have had three print runs of Stories to Tell edition 1. Back in 2013 the Stories to Tell was sponsored by the Office of Disability Issues and the then Minister Tariana Turia had this to say about our first edition:

'Once upon a time...those magical words have captivated our children and given joy to both storyteller and listener for ever 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 more than 2,000 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 million dollars invested into the Think Differently campaign.

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## “IT’S NOT A FAIRYTALE IT’S OUR TALE”

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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 provides 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”.

Today marks the release of these stories into the world. Over the next fortnight, Parents of Vision Impaired intend to tell their stories to the Thorndon community as part of their campaign of awareness for and of their blind and visually impaired children. The fabulous high tea that forms the concept in this event is so fitting for the nature of the

Thorndon Project. This is where a sense of history is captured between the pages of this resource. For over half a century the New Zealand Foundation of the Blind operated an office in Tinakori Road. Many a lifelong friendship was formed at the children’s Christmas party held in the rose garden.

And it was in this part of town, that the mayor of Thorndon was first elected in 1941 — a tradition which was carried on with annual contests for the mayoralty right up until 1985. Apparently the crowning of the mayor of Thorndon was a prestigious ceremony — complete with clowns, parades and a variety of bands. A modest fee was charged — just a penny to vote — and before long a sizeable fund was established. That fund — the Mayor of Thorndon Blind Kiddies Appeal — lives on today in funds and grants made to children right across Wellington.

In the opening page of the book, the rationale, then for the Thorndon Project is laid out. We are told, “parent support networks....survive on stories”.

The word, ‘survive’, is profound in its application.

For some — like Amanda — her story began in tragedy with the loss of her twin sister. Both girls were born with inherited retinoblastoma. Her story is entitled, ‘it’s not a fairytale — it’s our tale’.

The struggle for survival, in fact, resonates through many of the pages.

Joshua arrived in the world twelve weeks earlier than expected, fighting for his life from his first breath. His little feet were not much bigger than the wedding ring his 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.

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**“MY ADVICE FOR  
PEOPLE LIKE ME IS TO  
BE STRONG AND DO THE  
BEST THAT YOU CAN”**

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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 thirty 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 – and 44 years later 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.

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.

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 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 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".









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