

# Vision

Issue 99½  
December, 2013

"VISION" is the Official  
Publication of Parents of Vision  
Impaired (NZ) Inc.



## Intensive Wraparound Service. Is it all the Ministry of Education claims?



### **PVI's Whakatauaki/Proverb:**

*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 wide spread, May the sea glisten like greenstone,  
May the shimmer of summer dance across your pathways, May you always find peace.*



## Sub Editors' Editorial

With our Editor laid low in hospital a meeting of the Sub Editors was convened to produce Issue No 99 ½. As

we sat around sharpening our sub editorial pencils the question was....What shall we talk about then? Someone suggested CVI and someone else said what is that?

Well evidently CVI or Cortical (or Cerebral) Visual Impairment is the leading cause of bilateral visual impairment in the United States. In a study of students attending schools for the blind in the US, just reported in the Journal of The American Association of Pediatric Ophthalmology and Strabismus, the three leading causes of childhood blindness and severe visual disability were CVI (18%), optic nerve hypoplasia (15%) and retinopathy of prematurity (14%). In New Zealand according to the Royal New Zealand Foundation of the Blind CVI is the most common eye condition (over 28%) in children registered.

One medical professional commented that because CVI is caused by brain damage, vision impairment is often only one of the delays in a child's development with which teachers and parents must work. Communication disorders and motor delays are also common in children with CVI.

Children with CVI show no damage to their eyes. The cause of their inability to see is that the brain does not consistently understand and interpret what the eyes are seeing. This condition is one of the unintended

consequences or recent advances in neonatology and the resulting survival of very low birth weight babies.

So we can say that in New Zealand we have many families and children dealing with the consequences of CVI and yet we have a poorly created infra structure to deal with these children. The medical profession seem rather oblivious of the big wide world these families are entering and the demands placed on them. Maybe they should be talking to us more?

While the Ministry of Education appear to want to solve many things with their intensive wrap around service, they also want to close other special school facilities that are a life line for many parents and families. As these children move through the education system and into the great wide world beyond the sub editors wonder whether the Ministries of Health, Social Development and the myriad of support agencies that succour on the government funding pipeline are really prepared to provide co-ordinated supports that will be required in the future. These are million dollar kids in very sense of the word.

After the Sub Editors pencil sharpening conference we want to remind all our parents and families that we are a parent network support. If parents want to talk to a fellow parent we have an experienced national board that are available and regional representatives all listed in this newsletter and on our website [www.pvinz.org.nz](http://www.pvinz.org.nz) and a parents of vision impaired facebook discussion group. Our contact details are listed on the back.

***We wish you all a festive Christmas and a happy new year 2014.***

This has been an interesting year for the RNZFB

Children's service. We have lost one staff member, and recruited five.

We have refined and slowly rolled out our PACE handbook, still some way to go before it's widely used, but feedback to date indicates that parents love it and it gives them an indication of what their child can work towards.

Whilst the children's service will still refer to the PACE programme the RNZFB has a new name and look which will launch in the next edition of Outlook, which is distributed on December 12. The Blind Foundation. It's a simple, clear and more impactful name. While our everyday name will be Blind Foundation, the legal name of Royal New Zealand Foundation of the Blind remains. Sometimes Blind Foundation will be accompanied by the strapline 'Beyond vision loss' which tells people a little more about us.

There is also a new logo inspired by the concept of braille. Stylised contracted braille spells the words 'Blind' and 'Foundation' in a circular motion. The bright colours of red, orange and yellow dots show the vibrancy and confidence that people wanted to portray.

We are all looking forward to 2014, and would like to take this opportunity to wish you and your families a very safe, joyful Christmas and a happy healthy New Year.

Karen Connolly, Head of Children's Services

## Merry Christmas to All





# PVINZ Chair Report year ended 30 June 2013.

Tena Koutou

It is hard to believe it is almost a year since we last gathered to celebrate the joy of parenting. As much as we love this role, I think that we will all agree it is good to have a day or so away. I write this report from Melbourne where I am spending time with my daughter Haley her partner Joe and our mokopuna, Taylor 18 yrs, Blake 10 yrs, Hariki 8 months and Kahu partner to Taylor. As I think about my beautiful mokopuna, I am reminded of the meaning (Sacred blue print) each one of them carrying the whakapapa (DNA) of their parents, grandparents, great grand-parents and so on.

As I look to each one, the blue print and branches of the ancestral line are apparent and the stories that follow each generation held for our future. My mind wanders to my own line and I remember my parents, grandparents and great-grandparents and the role that they have played in my life.

We all have stories to share and this year has for PVI been an opportunity too. We begin with participation at the SPEVI conference. You would all have read in your "Vision magazine" how well we were represented and how stories shared touched the hearts and souls of our listeners. Thank you to Dionne, Kim, David, Paul, Judith, Tim and your families.

The Thorndon Project "Stories to tell" was a highlight for me. I particularly enjoyed the jazz concert and the church in which it was hosted. Our evening at Parliament wasn't too bad either. You should feel proud of your Board members and parent support during this campaign. I hope that you will enjoy reading your copy of "Stories to

tell". Thank you to David and Rhonda, Paul, Judith, Don and Linda, Paulette, Christine and families.

It was lovely to catch up with Kevin, Jo-Ann and Amanda who has blossomed into a beautiful young woman.

To the families who have shared their stories- He mihi aroha (greetings of love).

We held two seats on the Ministry of health "Child Spectacle Subsidy" review reference group with good outcomes for our Tamariki/Children you can read about them on the MOH website. Board members David and Don, who hold seats on the Boards of the RNZFB and BLENNZ respectively, have ensured that our voices are well and truly heard.

Auckland Board members Grant and Paulette have worked hard and provided extra support for our board meetings that have been held on the BLENNZ site.

Paul continues to work tirelessly for us all and I know that you will hear more about these achievements over the weekend.

I must thank each board member and their families individually and collectively for their dedication and commitment to this kaupapa (Organisation).

I have no doubt that the year ahead will bring both celebration and challenge, but for now let's enjoy one another there are "Stories to Tell"

*Ma te Atua koutou he manaaki.  
God Bless  
Riripeti Paine Chair PVI*



# Executive Officer's Report year ended 30th June 2013

*To my fellow parents,*

I am delighted to be able to report to you, this year a more positive situation for PVI, our financial position is sound, more government funding and an extra PVI Parent Support Worker.

This year we have employed two PVI Parent Support Workers, Justine Edwards working for the Waikato region and Mary Fisher working in the greater Wellington region. This support is different from the support provided by our staff at either BLENNZ or the RNZFB. We believe and other parents confirm that this parent to parent support is what our parents are appreciating. This support is what PVI was founded on. To be able to employ parents for their knowledge to support other parents is a further example of PVI valuing "parent knowledge".

We have applied for funding to appoint a position in Auckland and are to soon commence to seek a position in Christchurch.

To all of our funders the RNZFB, MoE, Lotteries NZ, BP Volunteer Vouchers, Masonic Lodge

Hamilton, Making a Difference funding from the Family and Community Service of the Ministry of Social Development, our sincere thanks, without your support our achievement would be much less.

I shall now report as per the PVI Strategic Plan.

## **1: To support parents/whanau so they are empowered to support their children:**

Support is provided through the National Office often via telephone on the 0800 312 019 number and many emails. We can report an **increase in "direct parent contact"**. **This we put down to the PVI Parent Support Worker role.**

## **2: To Grow PVI:**

Our parent membership continues to grow albeit slowly, which is a good thing really! We have conducted a major upgrade of our database with the RNZFB. This updating still continues weekly.

An improvement in the referral from RNZFB and BLENNZ staff is providing a steady and increased flow of parent enrolments. Our thanks to the RNZFB and BLENNZ for this support.

## **3: Building a Healthy Community:**

Through the PVI Support Worker role, the PVI closed "facebook" parents are being kept up to date. They have

an avenue where support is provided.

This has led to further

**"direct parent contact",**

a "Family Camp"

occurred mid August of last year.

PVI is part of the Blind community and as such we have positive relationships with Blind Citizens New Zealand (formerly known as ABC), Ngati Kapo, Retina NZ, NZ VIEW, the RNZFB, DeafBiind NZ and of course BLENNZ. We meet on regular occasions through the Blind Consumers Consortium of New Zealand and the Blind Sector Education Forum. At these meetings, we share relevant information and discuss points of concern with a solution focused approach. These meetings are good for developing strategies for further improvements in service for our children.

Our relationship with the Child and Young Person's Service of the RNZFB continues to grow. PVI is delighted with the introduction of more specialist skilled staff in the children's service of recent times.

On a wider basis we have strong relationships with the Ministry of Health (MoH), the Ministry of Social Development (MSD) and the Ministry of Education (MoE). These are the three major ministries affecting our children. With the MoH, we were engaged in the Review of the Children's Spectacle Subsidy (CSS). Here we managed to, not only maintain the government spend, but increase the funding to better meet the current demand. We were also able to maintain current access for families. We are also involved with the Ministerial review of the Special Education School Transport Assistance known as SEST A. Here we are looking at a more inclusive approach to school transport assistance, the possible use of minders on school transport, and a better complaints process for all parties involved. It is interesting work and at the heart of our conversations are our children and the safe transportation to and from school.

We embarked on a Disability awareness programme this



year during the month of June. The **“Thorndon Project - Stories to Tell”** was officially launched in the Grand Hall at Parliament on the evening of the 10th June. We were hosted by **the Minister of Disability Issues Minister Turia**. Of the 80 or so that attended, we witnessed a magnificent speech from the Minister, where she referred to the **“Stories to Tell”** publication. To each of the stories, she captured the essence of parenting and living with disability. Another highlight of the opening was the speech given by our Chair, Ms Riripeti Paine, whose presentation was the highlight of the opening, absolutely captivating.

Feedback from the government officials was very positive to say the least. On the evening of the 20th June, we held a **Jazz concert at the “Old St Pauls church”**.

The jazz group comprised of two blind musicians ... an absolute stunning evening. The storm that hit Wellington that evening only heightened the musical performance.

**Caitlin Smith and her amazing vocals, Mark Lockett on drums** and the driving force behind the concert and subsequent CD ensured a quality performance. The **CD called Caitlin Smith and “Stories to Tell” can be purchased from PVI for \$25.00 each.**

Major advocacy work involves, supporting PVI parent's concerns, on the Carers Alliance of NZ Executive re Payment to Parents as Carers of adult disabled children, payment to Carers via the NZ Carers Strategy via a new five year action and implementation plan from Government.

Many of you will be aware of the shocking position family carers have been placed in by the government's decision to deny parent/unpaid carers the right to appeal any decision regarding payment of care issues; the denying of carers to be paid to provide care for their spouse is another example of this bad legislation.

PVI is represented in the **Waikato - Enabling Good Lives Leadership Group**. Here we are charged with the implementation and oversight of the development of ensuring Enabling Good

Lives principles are the driving focus of Service Provider, Family and Persons with Disability interests. In short, the person with disability and their family will have **THE SAY** in how funding is allocated in the future. This will affect funding for transition from school to life beyond, day services programme/vocational programmes with a focus away from the 9am - 3pm focus as at present and residential options. Residential and vocational placements maybe with a service provider or with the community which is becoming more and more popular. The big point is parents and the person with disability will have **THE SAY** in how the funding is spent.

Funding is to be pooled, no more silo mentality, much more flexibility ... at last.

With our “Vision” magazine we have produced 6 in the past financial year and have opted for them to be printed off site. This has led to a considerable savings for PVI. I continue to get positive feedback about “Vision”. With “Vision” we try to target an audience of parents with younger children through to parents with adult children, such is the scope of our membership.

#### **4: Moving forward together:**

I wish to make comment of our ability to operate within a sustainable funding model. With the halt to a further decrease in funding allocated to consumer organisations by the Royal New Zealand Foundation of the Blind (RNZFB) has meant two years on the same level of funding. This level allocated by the RNZFB quite simply needs to increase if the RNZFB wishes PVI to better compliment its own services. We can prove that any dollar invested in PVI is a very good spend by the RNZFB; to have the opportunity to grow the budget is what we are seeking.

Funding has been sought from sources other than the RNZFB and we will continue to do so. However, other funders do not appreciate or understand the role of a parent raising a blind/ DeafBiind or Vision Impaired child often with additional complex needs as well as the RNZFB. It is because of this understanding, we believe the RNZFB should remain the major funder of PVI.

To my staff Lyn, Justine, and Mary my sincere thanks, your support is appreciated. To the PVI Board, my sincere thanks. They have worked hard with policy, support with fundraising and support in person at various meetings to promote the PVI perspective.

This year your Board met for six meetings, three face to face and three by teleconference, well done and thank-you for your time and valued support. Last but not least to my wife, Marie, thanks for supporting me.

In closing, to you my fellow parents rest assured I continue to strive for improved services around our children and us as parents. What drives me? I look at my daughter, Jessica, my wife, Marie, and my family, and believe there must be a better way that Enables a Good Life!

*Yours  
Paul Manning  
Executive Officer  
Parents of Vision Impaired NZ Inc*



# Letter to the Editor of Vision Newsletter: PVINZ Inc

Last month we experienced the warmth and vibrance of another Parents of Vision Impaired Conference in Auckland. It was a wonderful networking event.

We both listened with sadness to one of the keynote speakers Stuart McLaren explain his family journey through the education system in New Zealand with a complex needs kid.

We heard about the high achievements at Halswell Residential College, and the following despair at not being allowed to continue that achievement by an archaic Ministry of Education policy.

What followed for the family was a nightmare, and what we know now was a complete failure of the new highly publicized IWS Intensive Wrap Around service for our complex needs kids in New Zealand

This tragic case highlighted the needs of a child with an exceptional level of funding under the IWS and the failure of the IWS to deliver the goods!

The family was left with the option a residential independent school 300km away or a psychiatric hospital. As featured in the Dom Post recently, it is cruel to place any individual in such a facility when they don't need that level or type of care. THE IWS policy ironically changed this year to allow residential placement in one of the 3 remaining residential schools as a component of the service. While this may have temporarily solved the problem it would not provide any long term solution and what would happen after IWS ended? His schooling finish that very day?

What sort of solution is IWS when the family had to resort to paying \$8,500 to attend a residential placement 300km from home?

Following conference we were so concerned we started to research this so called wonder fix IWS. What we found was disturbing. We read all the justifications at the Ministry of Education Web Site and then took a look at their referenced research!

What we found was not research but over 100 pages of a literature review by Dr Mitchell from Canterbury University ... we read further ... and further. No research just ideology. It was one sided from the stand point that all children can be included with any counter argument dismissed or ignored. There was no anecdotal or other programmed research applicable to New Zealand! The case study presented by Stuart McLaren is due for publication in a refereed journal and presents an in-depth analysis of an actual case in New Zealand and what went so wrong. This is far more relevant to the whole debate. However we are aware of parallel cases in New Zealand Schools where inclusive education has failed despite the best intentions of all. Why these cases are always buried as if they didn't exist? It is disturbing that in cases where children have nowhere else to go that they are being enrolled in schools but they only attend for a couple of hours a week. This of course disguises the legal requirement of attending school. Is this inclusive education?

We dug a little deeper! We found the so called research provided to support the closure of Salisbury Special Residential School in Nelson was provided by the same Dr Mitchell from now Waikato University. Not research but yes of course a literature review. Again no anecdotal evidence or formal studies conducted in New Zealand.

Again an essay to support the Ministry of Education stance to close Salisbury School.

The rest is history: The majority of submissions supported the continuation of Salisbury Residential Special School. The High Court supported the majority.

So we sit and wonder as parents where is the consultation with us and with our parent constituency.

We sit here and watch the IHC sponsored Inclusive Education Action Group conducting seminars around the country at the moment and again are promoting the concept that all children no matter how needy can be fully included in mainstream education. By their own definition this is an activist group with an axe to grind and can hardly be called independent and unbiased.

This activist group have consistently undermined the special school education system. They only ever recognise one side of the story and are in total denial of the many cases of children with severe and multiple needs which are such that they cannot be included in an inclusive classroom of 30 children (no matter the level of resource and support).

This group fail to recognise the harm that they do by systematically undermining the few options for the severe and multiple disabled children.

As parents we do not believe that IHC New Zealand has any parent mandate to push such a policy! Just how many parents do they represent? As a family we do think too many?

The IWS program needs to develop and be properly resourced and as a family we strongly believe it needs to coexist with all the special schools, special units and residential placement options presently available.

The Ministry of Education need to stand up to the demands of the IEAG and to start listening to parents and families throughout New Zealand who want choices for their disabled kids. IEAG have no mandate to suggest closure of all special education facilities in New Zealand.

As a family we are hopeful that Minister Parata and her Ministry of Education will start to consult and talk with all parents of disabled kids and listen to their needs and aspirations. As a family we sit and worry that the energy and advocacy we have used to develop a world class education model for our blind and visually impaired children under BLENNZ might be compromised by a short sighted IWS strategy that has not been researched or tested in New Zealand.

To Stuart and Debbie McLaren we say thank you for your courage and advocacy.

*Sincerely, Concerned Mum and Dad*

## Dear Sub Editor

The recent conference discussions about support for our complex needs children prompted me to put pen to paper. The bureaucracy surrounding our experience is I believe typical of the challenges parents face!

Even though our child receives the maximum Teacher aid hours allocation available, and brings to the school one of the highest funding packages available, she was still a constant victim of "If your child gets this, other children will miss out." It came across as a blatant attempt at emotional blackmail, and an opportunity to paint the parent as the "unreasonable bad egg" should they have the audacity to insist. In other words, thanks for the money and the teacher aid time, now we'll spend it on others who didn't qualify.

For five years, we requested at every single IEP for our child to go swimming three times a week. As the school does not have a pool, this has to happen in town, which is within walking distance, or in her case, electric wheelchair driving distance. The reason swimming is so important is it translates into pure physiotherapy, exercise, independence, self-confidence, self-management, and social interaction with members of the public. I rank the physio and exercise as crucial, and we have found no other way to achieve this. It is vital to her well-being. (joint development and maintenance, bowels, balance, spinal alignment, weight-bearing, prevention of muscle ligament and tendon contractures, etc etc. This child has had over 30 surgeries, so yep, it's vital.) She has no comprehension of the usual subjects like maths, geography, science, art, etc, so it has been no loss academically for her to take this time out of mainstream classes.

Every single IEP, we have been denied this, on the grounds that there is

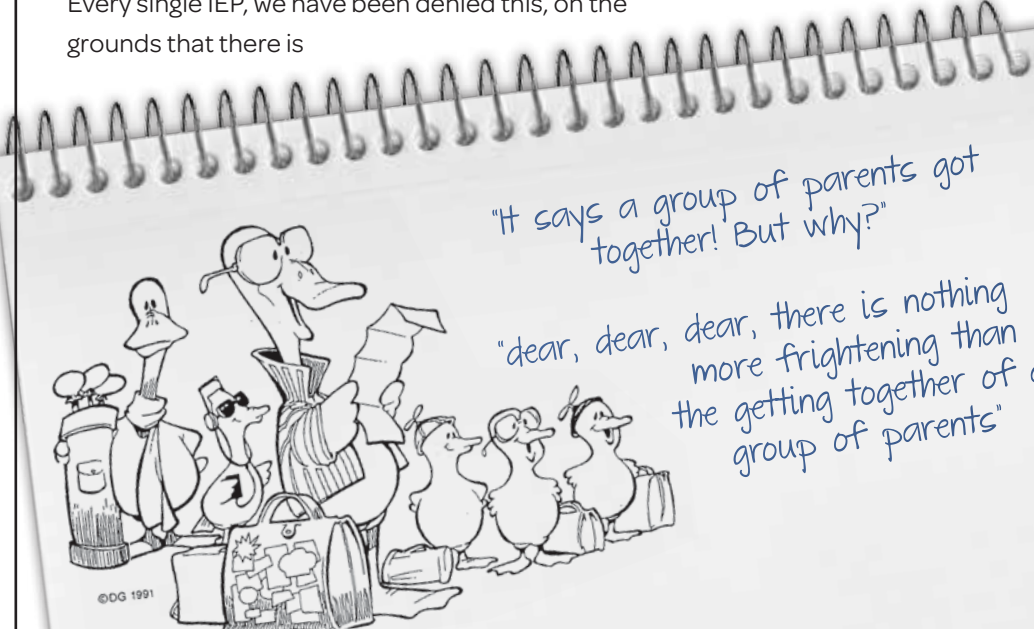
insufficient teacher aid time available. It was spelt out in no uncertain terms that if the school were to do this, other children would not have any teacher aid available as they were piggybacking on her allocation, ... therefore no, it was not possible. We were reminded constantly that the school had x number of students requiring teacher aid time, and only x number of hours allocated, so it was a difficult job for the SENCO to balance it all, and we had to be fair on the other pupils. In other words, we will use your teacher aid time for the kids that don't have any, or not enough.

In the end, we were only able to negotiate 2 swimming sessions a week, and only if we paid for a wheelchair taxi to and from the pool for her and the teacher aid, and all costs of entry to the pool for them both. And we felt very fortunate indeed to achieve that!! The school receives one of the highest funding packages available for this pupil!!

Another difficulty we experienced a few years ago was when she transitioned to a new school. The orientation and mobility instructor had a report commissioned prior to her starting, on safety issues within the school for a severely vision impaired child. It resulted in a two page report. However, the school decided things like painting the edge of steps to identify them, and other such matters, would impact on the appearance of the school in a negative way, so they refused to action even one single thing on that report. And I can tell you, it almost impacted very negatively on our daughter when she drove her electric wheelchair down a flight of stairs by mistake one day. The teacher aid with her saved her bacon by grabbing her around the chest and hanging

on tight to stop the 150kg wheelchair somersaulting, and another adult came to assist. The teacher aid was so traumatised, she suffered such severe heart palpitations later that evening an ambulance had to be called!! But hey, the school still looks great.

*Mother from the Deep South*



"It says a group of parents got together! But why?"

"dear, dear, dear, there is nothing more frightening than the getting together of a group of parents"

# 20 Stress Crushers

*FIND • Kaset International- 8875 Hidden River Parkway, Tampa, FL 33637-813-977-8875*

1

Play pinocchle, ring toss or dominoes. They're better for you than the other games people play like "who's got the biggest house, most important job or highest priced car?"

2

Don't hold onto dynamite after it's lit. Walk away from quarrels, fights, or squabbles when tempers are touchy. Don't argue. Discuss.

3

Train, don't strain. Increase workloads and responsibilities gradually. Don't take on more than you can handle.

4

Love thy neighbour as thy old slippers. Be casual and comfortable with people. Accept them as they are. Enjoy others.

5

Find your funny bone. Laugh at yourself and at situations. Humour melts stress.

6

So, who cares? Maybe today, but 500 years from now? Or even 5 years from now? Put things in their right perspectives. They may not be as important as you think.

7

Don't tie tin cans onto dogs tails. Be kind. Respect the feelings of others. Be nice to everyone. Let relationships run smoothly.

8

Go to the North Pole. Or a cave, attic or bomb shelter where you can be by yourself. Try to be alone for a few minutes each day just to relax, meditate or read.

9

Avoid leaping contests with kangaroos. Don't compete with everybody doing everything. Refuse to compare yourself to others. Set your own standards.

10

Are you a magnet or flypaper? Do you attract positive things and people to your life, releasing them easily and naturally if they aren't right for you? Or do you get stuck with a lot of nuisances and burdens that won't go away?

11

Be a big spender. With love, that is. The more you give, the less stress you will have.

12

Pity the poor worms. They get eaten by birds. Big fish gulp down little fish. Wolves devour rabbits. Pour out your sympathy on those little creatures but not you.

13

Don't buy the cow to get a glass of milk. You don't have to buy an airline to visit your Aunt Emma. Don't make big deals out of everything. Simplify life. Take on a little bit at a time.

14

Get lost in a dream. Always be working on something larger than the weeds by the rosebush, car payments, or dusty closet shelves. Tomorrow's dream takes the stress out of today's problem.

15

Retire from the Supreme Court. Get out of the human judgement business. Why add to your stress level by useless critical opinions of others?.

16

Pretend you're on four wheels. You'd never abuse your car like you do your body! Exercise. Get sleep. Booze, coffee and cigarettes don't reduce stress- they increase it.

17

Pin a medal on yourself. Reward yourself when you've worked hard. Have some lobster, go out dancing or see a show.

18

Get a babble buddy. Find someone who will listen. Talk about your problems anxieties and fears without shame.

19

Ride a rainbow. See something pretty in what's about you. It's really quite a lovely world if you take time to look at it!.

20

Take slowpoke training. Slow down. Allow more time for tasks, getting to appointments, eating meals, and relaxation.



## Part 2 from Proud Dad LAURA and SHADOW

As written in a previous Vision Newsletter in April, Laura aged 15 and her lovely pony Shadow are a team and love each other.

Laura decided she wanted to trial for the Tauranga Show jumping team this year and after three trials she got selected.

Laura had the smallest pony as all the rest competing were on hacks. A pony can be up to 14.2 hands high. A hand is 4 inches. Shadow is 13.2 hands high. A hack is over 14.2 hands.

On her final test she cleared every jump of 90cm. Everybody else either clipped a rail or knocked them off. Her mate and riding mentor Olivia clipped about 5 rails.

Laura gained the most points beating her mate who had taught her to jump.



In other events during the day Laura had done very well as can be seen by her ribbon count.

So on the 15th December we are off to Rotorua to compete in a major competition.

The last two or three club competitions she has entered she has done really well also.

## Today you Can!

**Dionne Gilligan, PVI national executive member from Whanganui reflects:**

"I think as parents we can sometimes feel as if we are just living day to day, and week to week, just to get through. But if we look back we are amazed at what we have learnt, what we can do, and have done.

No it is not all ways easy, sometimes it's really really hard but we do what we do for the love of our children and what we learn is a bonus. Sometimes things are not achieved on the day we want or the that week, but as most of us parents know it's the squeaky wheel that gets the attention! "

### Today You Can

*by Catherine Pulsifer*

Today you can choose to count your blessings  
or you can count your troubles.

Today you can live each moment  
or you can put in time.

Today you can take action towards your goals  
or you can procrastinate.

Today you can plan for the future  
or you can regret the past.

Today you can learn one new thing  
or you can stay the same.

Today you can seek possibilities  
or you can overwhelm yourself with the impossible.

Today you can continue to move forward  
or you can quit.

Today you can take steps towards resolving your challenges  
or you can procrastinate.

You see today the choices are up to you  
in deciding what you do today.

# 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

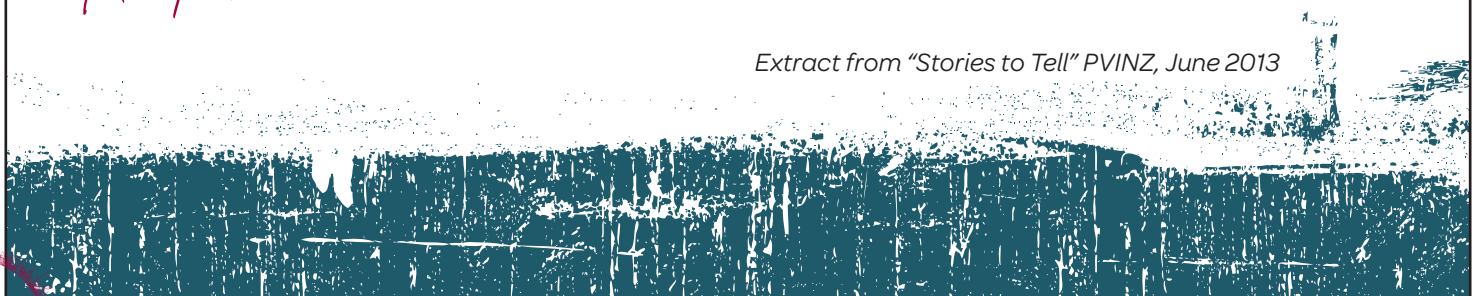
"Tirohia ake nga whetu  
Me ko Matariki e arau ana  
He tiki mai tahau I nga mahara e kohi nei  
Whakarerea ake  
Na te roimata koua riringi  
He puna wai kai aku kamo"  
  
*"As I look to the stars and the brilliance of Matariki  
I remember loved ones who have returned home  
My heart yearns for them  
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

Extract from "Stories to Tell" PVINZ, June 2013





# ANNOUNCEMENT FROM BLENNZ

I am writing to you all as the Chair of the Board of Trustees of BLENNZ, the Blind and Low Vision Education Network NZ, to advise the outcome of our search for a new permanent Principal. I am delighted to announce that, following an extensive search both in New Zealand and overseas, we have appointed Karen Stobbs to the position. Karen has an outstanding breadth of knowledge and experience in blindness education. In more recent years, She has dedicated herself to developing the national plan for education of blind and low vision learners, and ultimately the establishment of BLENNZ itself. She has huge passion for ensuring all blind and low vision learners can reach their full potential and be fully productive members of Society.

The Board is confident that Karen is the ideal person to lead BLENNZ into its next phase of development, and we look forward to working with her and all of you as together

we pursue that goal.

The Board has also decided that it is now time for the Principal of BLENNZ to no longer be based specifically at the Homai campus. We believe this is a logical step to take, now that BLENNZ really is fully established as a truly national organisation.

I am sure you will all join me and the Board in congratulating Karen on her new appointment.

*Clive Lansink, Board Chair*

Email: Clive@Lansink.Co.NZ, Phone: +64 9 520-424, Mobile: +64 21 663-999, Fax: +64 21 789-150



*Nico Gilligan*

## GETTING READY FOR A MEETING Judi Stotland.

- 1. PREPARATION:** Talk to other parents, and any professionals who will speak with you. Read books that don't make you uncomfortable. Make a list of questions and bring it with you to the meeting.
- 2. BRING A FRIEND:** Don't try to do this alone. Pair off with another parent of a handicapped child, a neighbour, or a friend. Call on your support system as often as you need it, and **DON'T WAIT UNTIL IT FEELS LIKE AN EMERGENCY!**
- 3. GIVE FAIR WARNING:** If you are bringing other guests to the meeting, let them know in advance. If you have many questions for the doctor, let his receptionist know this when you make the appointment. Ask who they expect to attend.
- 4. DRESS FOR SUCCESS:** A doctor's appointment or IEP is a business meeting. Dress like you would for a job interview.
- 5. TALK TO YOUR CHILD BEFORE THE MEETING:** Will he be coming along? Does she have questions to be answered?
- 6. CALL IF YOU ARE RUNNING LATE OR NEED TO RESCHEDULE.**
- 7. DON'T GET CONFUSED BY UNFAMILIAR WORDS:** To be an effective partner in a meeting, you must have things explained until you understand them.
- 8. Be ready** to report what you know about your child's current functioning and health.
- 9. Share evaluations** from other professionals, if they are asked for, or you think they are especially useful.
- 10. "Why is this test necessary?" and "I'm not sure why this should be a goal for my child."** are good points to make with professionals, especially when they are asking for your consent.
- 11. WRITE DOWN THE ANSWERS TO YOUR QUESTIONS AS YOU HEAR THEM:** Things get muddled in emotionally charged meetings. If you take notes, everyone will know you are serious about learning what is being said.
- 12. Try to get all commitments in writing.** If someone says something will be done, try to find out who is responsible for doing it, and by when.
- 13. Don't feel pressured into agreeing with a plan on the spot.** You are entitled to think it over, and to change your mind.
- 14. Nothing is a commitment forever.** If circumstances change, or you think of things to add, talk with the professional about making the needed changes.
- 15. PhE means Parent Having Experience.** You are the expert when it comes to your child. You are entitled to respect for who you are and what you are doing. You are entitled to disagree with the other experts, and to have your vote win if they cannot convince you to change your mind.



# Understanding Transitions

by Christina Clapperton, Guest Writer



Any parent or other close family member of a child transitioning into adulthood knows what a trying process it can be when adult services are needed. Transitioning into adulthood is usually the most difficult time for both the parents

and their children. While you are doing everything you can to ensure that the process doesn't exacerbate the stress that any teen experiences when transitioning into adulthood, you may be going through your own transition, such as an illness. We may not think of illness as a transition, but when it becomes lengthy and the prognosis is not looking favourable for a quick recovery, all aspects of our lives are affected - anything from our ability to maintain employment to enjoying activities that good health affords. The encouraging news is that there is always something that can be learned from transitions that can ease the struggle.

In his book *Transitions: Making Sense of Life's Changes*, William Bridges outlines three stages that occur with any transition: An ending, a neutral zone, and a new beginning. The reader is likely to be surprised by his claim that transitions begin with an ending. But we might be inclined to agree that when we go through a major life transition, we lose a semblance of ourselves before a new self can take shape. The feelings that characterize the next stage - confusion and anxiety - take place in the neutral zone. Because the neutral phase is foreign to us, we lapse into one of two directions: We either hope to reach the new beginning prematurely or we wish to return to the familiar past. While transitions can affect our lives in ways that we perceive as unfortunate, people who experience adversity stand to gain the most because challenges are also opportunities that can inspire motivation to make our lives better than they were before the transition.

An illness can also lead you to recognize what is going particularly well but that could easily go astray when we don't attend to them. And if you recover from your illness, take a moment (or many!) to be amazed at how resilient the body can be. Given the mind/body connection, a resilient body is often the result of a resilient mind. When illness slows you down, you can benefit from using the time to make small improvements to your character that will outlast the neutral zone and give you strength to take

**There is much that transitions can teach us.**

**The loop in which we are thrown can lead us to step back and reflect on other areas of our lives, ones we have more control over at the time. When we do this we might be urged to make an effort in all aspects of our lives.**

on future challenges ahead.

Aside from moments when we are so absorbed in a task that we don't notice pain, illness tends to follow us around in all of our activities. We all know that simply being tired makes everything that much harder. But energy levels fluctuate and eventually the energy will be returned to you.

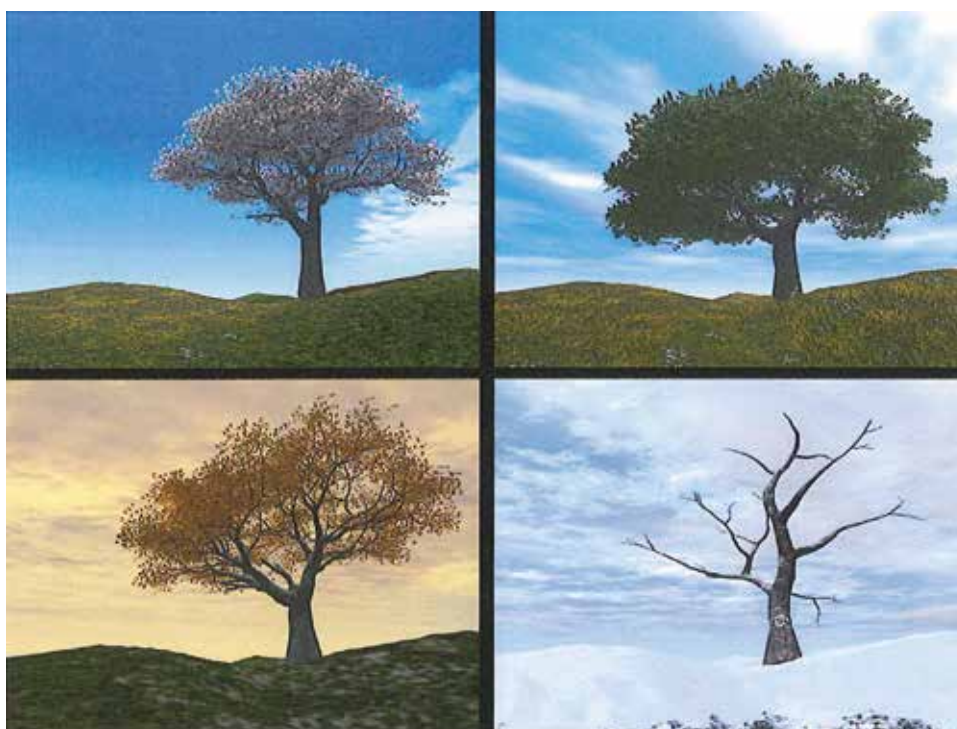
Illness often works in the same way. Whether it is a bad day or a longer period of time, we need not assume that it is a relapse or progression of the illness. We do our due diligence and consult a medical professional in cases of new or increased symptoms, but if we are told that peaks and valleys are expected, we can rest in knowing that an increase in pain is often a phase. When days or weeks go by without a reduction in symptoms, we are hard-pressed to believe that it will get better. But recall the saying, "this too shall pass."

Viewing situations on an individual, micro level is a lonely experience. You feel that the only way someone could understand you is if they inhabit your body - just for one day and feel what you endure. People will tell you, "I know how you feel." This is untrue. What they mean is that they can relate to the process of what you are going through as we all, at some point in our lives, experience the same emotions. As physical and psychological pain are more intertwined than we usually realize, we may hold ourselves back from reaching the next phase. Pain does not equal suffering. Rather, suffering is more often the result of how pain is viewed. By understanding the trajectory of transitions, we become better prepared for them. Bridges talks about the idea of seeing "our transitions. We may find it helpful to "watch" the phases and "see" them rather than float along without the wisdom that comes with knowing why we feel the way we do at a particular time. While the specific details of the phases to come remain unknown to us, we can anticipate the process. Through awareness of the phases

-the ending, the neutral phase, and new beginning - we can learn to see our transitions unfolding before us and perceive the feelings as temporary.

Seeing the transition as a “slice of life” that is part of a larger cycle helps us understand patterns to the illness. This moving and unfolding of patterns is a contracted version of the patterns that life takes only greater in magnitude, such as the changing of seasons. Seen in this way, we can appreciate transitions as unavoidable and, therefore, something we shouldn’t expect to change.

While illness is never easy to handle, and might be further complicated by multiple, simultaneous transitions, such as those that your youth is experiencing, we can assure ourselves that phases come and go in their own time. If we see the phases rather than passively moving through them, we might understand them as smaller versions of larger, natural phases - processes that represent the whole of life. I encourage anyone going through a transition to read Bridges’ book. It lends a wealth of information and personal stories to guide you through.



*Christina Clapperton is going through her own transition, leaving her role as Research and Communications Coordinator at FSI to return to school. We wish her luck in her master’s program where she will be studying Society, Culture & Politics in Education.*

# Websites and Info Bites

**www.pvi.org.nz** This is our website, please use it....

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**Free-phone 0800 312 019 Email: paul@pvi.org.nz**

**www.blennz.school.nz** The new **BLENNZ** website, take a look, well worth the effort! Word-class, a global leader!

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**www.kapomaori.com** The official website of Ngati Kapo Aotearoa Inc

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**www.abcnz.org.nz** The largest Blind Consumer group in N.Z. An excellent website.

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**www.humanware.com** Products for both Vision Impaired and Blind users.

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**www.pacificvision.org.nz** This website has links to many international providers of Low Vision aids.

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**www.biopicdriving.org** This website explains how some vision impaired people can gain extra vision by using biopic lens that in some cases enables them to drive legally!

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**www.aniridia.net:** Anidiria Foundation International.

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**www.aniridia.org:** Anidiria support

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**www.albinism.org.nz** New Zealand's website for those wishing to know more about Albinism.

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**www.nzord.org.nz** This website has links to many international sites containing information concerning rare disorders. This site is the New Zealand link.

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**www.rnzfb.org.nz** The website of the Royal New Zealand Foundation of the Blind. **Email general@rnzfb.org.nz**  
**Free-phone: 0800 24 33 33**

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**www.quantech.com.au** This website has good info new Mountbatten training resources. Worth visiting if your child uses braille.

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**www.tsbvi.edu** The Texas School for the Blind and Vision Impaired is a leading educational facility. Excellent information and links to other places.

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**www.minedu.govt.nz** The official Ministry of Education website. Good information, easy to use.

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**www.varietyclub.org.nz** The Variety Club may be able to provide financial assistance for children with special needs. I have found them most supportive and helpful in the past **09 522 3743**.

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**www.parent2parent.org.nz** Parent 2 Parent is a nationwide support group of parents who have children with special needs.

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**www.carers.net.nz** This is the official website of Carers NZ. This website has excellent information on a range of carers needs. They produce an excellent magazine called "Family Care". This magazine is free to all carers, just ring Sara at 09 406 0412 or email: info@carers.net.nz

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**www.napvi.org** The National Association of Parents of Vision Impaired USA. Good website, note the section re parent matching.

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**www.cpsociety.org.nz** NZ's Cerebral Palsy site an excellent website, very informative and easy to use.

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**www.wrightslaw.com** An excellent website for tips on IEP's, it is USA based where laws are different, the tips and ideas are very similar though.

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**www.zabonne.com** Zabonne's website hosted by Ivan Pivac, much information regarding blind and low vision aids, plus technology aids for children with additional disabilities.

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**www.maparentsupport.com:** - a web site for parents to find support from others who have children with Microphthalmia Anophthalmia.

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**www.bookdepository.co.uk:** - Cheap normal print books, price includes postage

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Have you tried **Tumble Books?**-through public library digital books.

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**The BLENNZ Library** ...fantastic range of books

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**www.atmac.org** for assistive technology for Mac OS X, iPod, iPhone and Apple Users

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**Whats App** - application to download which enables pictures to be sent for free by cell phone.

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**Market Place** - Phone app

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**www.facebook.com/pages/Homai-Formats-Library**  
As A PVI parent you can join the Homai Library face book team.

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**http://www.health.govt.nz/publications/subsidy-glassesand-vision-tests-spectacles-subsidy**

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**Needs Assessment and Coordination:**

**www.disabilityinfo.co.nz**

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**RNZFB Holiday Home:** The RNZFB have one Holiday Home available to rent for members. Located in Tauranga at \$50.00 per night. For further information contact Karen at the Tauranga RNZFB Office between 9.00am and 12.00noon on **07 578 2376**.

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Have you tried the PVI closed facebook ? It might be well worth a visit as many PVI parents mainly mothers are using it. Enter/to join: Parents of Vision Impaired (NZ) Incorporated, note only registered parents of PVI are allowed to join. Great avenue for sharing and learning

**www.yesdisability.org.nz:** Yes Disability Resource Centre in Albany. Note the Mothers support group known as Mum's@ Yes" Information Swap Network Group Meetings.

**A CD called "A Family Affair"**, available from **BLENNZ** Homai Campus, **09 2667109** it gives good information re the National Assessment Services available at BLENNZ.

**PacificVision:** email Barry at barryb@pvi.co.nz excellent low vision equipment.

**Parents:** - Feel free to write to the following Members of Parliament the good news (Positive Advocacy) or bad news concerning either your child's needs or yours as a parent!

- **Prime Minister:** pm@ministers.govt.nz
- **Minister of Education:** hparata@ministers.govt.nz
- **Minister of Disability Issues and Lead Minister of the Carers Strategy:** tturia@ministers.govt.nz
- **Minister Maori & Assoc Min Education:** psharples@ministers.govt.nz

#### **PVI Regional Support Vacancies:**

We need more parents to volunteer as Regional Representatives in the following areas:-

- Northland
- Sth Auckland
- Waikato

We need more parents acting as signposts to support other parents in your community. We wish to create teams within your own community hence sharing the workload. If you have a little time to give and wish to furthers.

**Please contact: ~ PVINZ on Free phone : 0800 312 019**

## **Well how about a PVI Recipe "Sweet Memories"**

### **Base:**

- 125 grms butter
- ½ cup sugar
- 1 egg
- 1 ½ cups flour
- 1 tsp baking powder
- ½ cup of jam (raspberry) is recommended.

### **Topping:**

- 1 egg
- ½ cup sugar
- 1 cup coconut

### **Method:**

- Melt butter in a pot big enough for mixing in the other ingredients.
- Cool slightly and stir in the sugar.
- Beat in 1 egg with a spoon.
- Sift in the flour and baking powder, mix to a soft consistency and spread into a greased dish (slice tin is a good size).
- Spread base with jam.
- Lightly beat remaining egg and combine with second measure of sugar and coconut mix well.
- Spread mixture on top of base.
- Bake in a pre-heated moderate oven for about 30mins, turning down the heat to 150°C after 15mins.
- Mark into slices while still hot, but leave to completely cool in dish before turning out.

## **New part time position**

### **PVI PARENT SUPPORT WORKER - C A N T E R B U R Y**

**Work with parents to empower and support them, by maintaining a record of regular contact thereby developing a supportive relationship**

You will have:

Good written and communication skills

Empathy with parents raising a child with visual impairment and other complex needs

Motivation and initiative to develop and support PVI families in Canterbury

An ability to work unsupervised yet be accountable to the organisation

Experience in social work, community support and the disability sector

**To apply: Contact PVI Inc for an application form and position description. Email - lyn@pvi.org.nz**

*Applications close January 31, 2014*

# Your PVI Board

## Northern N. I. Representatives:

Mrs Paulette Francis: 09 835 1232  
paulette.francis@vodafone.co.nz

## Central N.I. Representative & PVI Treasurer:

Mr. D Fairgray: 027 286 7798

## Lower N. I. Representative: PVI Vice Chair

Mr David Heather: heatherdavid1945@gmail.com

## Northern S.I. Representative:

Mr Tim Marshall: tim4jenny@paradise.net.nz

## Southern S. I. Representative:

Ms. Judith Hyslop: 03 476 6666 judithhyslop@extra.co.nz

## Anywhere in N.Z. Representative:

Mrs. Dionne Gilligan: 06 344 7755 dionnesg@gmail.com

## Tangata Whenua Representatives: PVI Chair

Ms. Riripeti Paine: 06 838 3949

1 Position Vacant please contact Riripeti



Return Address:

Parents of Vision Impaired NZ Inc, PO Box 366, Waikato Mail Centre, Hamilton 3240

# Regional Support Parent Contacts

|                       |                                 |                            |                      |                                 |                             |
|-----------------------|---------------------------------|----------------------------|----------------------|---------------------------------|-----------------------------|
| <b>Dargaville:</b>    | Gaynor Edgar                    | 09 439 4439                | <b>Wanganui:</b>     | Amanda & Rex Van Elswijk        | 06 345 0327                 |
| <b>Wellsford:</b>     | Kim Lewin                       | 09 422 1012                | <b>Manawatu:</b>     | Jane Hoani                      | 027 878 8441                |
| <b>North Harbour:</b> | Linda Moore Carter              | 09 442 1330                | <b>Wellington:</b>   | Christine Pask<br>Joanne Beaver | 04 527 7585<br>04 589 3719  |
| <b>Auck. Central:</b> | <b>Vacancy please apply</b>     |                            | <b>Kapiti:</b>       | David & Rhonda Heather          | 04 293 6539                 |
| <b>Auck. West:</b>    | Paulette & Rodney Francis       | 09 835 1232                | <b>Blenheim:</b>     | Jane Sheat<br>Tirzah Shepherd   | 027 713 5524<br>09 530 9539 |
| <b>Hamilton:</b>      | Maxine Jeffery<br>Trudy Perrett | 07 853 7006<br>03 544 6641 | <b>Nelson:</b>       | Adrian Seeker                   | 027 2011028                 |
| <b>Tauranga:</b>      | Linda & Don Fairgray            | 027 286 7798               | <b>Christchurch:</b> | Andrea Lamont                   | 03 980 1566                 |
| <b>Rotorua:</b>       | <b>Vacancy please apply</b>     |                            | <b>Oamaru:</b>       | Pat Fox                         | 03 434 3499                 |
| <b>Wairoa:</b>        | Riripeti Paine                  | 06 838 3949                | <b>Alexandra:</b>    | Sarah Hinton                    | 03 449 2414                 |
| <b>Napier:</b>        | Lou Halbert                     | 06 845 4706                | <b>Dunedin:</b>      | Alaina Gillies                  | 03 484 7433                 |
| <b>Taranaki:</b>      | <b>Vacancy please apply</b>     |                            | <b>Invercargill:</b> | Kim Hartley                     | 03 217 1906                 |