



**Parents of Vision Impaired (NZ) Inc.**

**Annual Report**

**2013**



**"Stories to tell"**

## 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 18yrs, Blake 10yrs, Hariki 8months 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



## Treasurer's Report year ended 30th June 2013

Greetings to you all,

Once again another year has sped by, it only feels like last month I was delivering the 2012 PVI Treasurer's Report.

Once again Lyn Morgan our Office Manager has presented us with a brilliant set of books. Thank you Lyn.

Thank you to the RNZFB for their continued financial support of PVI. Our other major grants came from J.R.McKenzie Trust, Community Grants, William Downie Stewart, NZ Lotteries, Hamatana Masonic Lodge, Wel Energy Trust, Family and Community Services of the Ministry of Social Development for the Thorndon Project—Stories to Tell, and Ngaruawahia Lions thank you for your support.

We have made a small surplus of \$4,714.00. This is mainly due to the excellent work of Paul and David chasing and getting sponsorship money.

Fundraising is a very time consuming job that takes PVI away from its core business advocating for our blind and low vision children. We need to do this fund raising just to survive. My biggest worry with chasing additional funds like this is that we are competing against our major fund holder the RNZFB for funds and the public could get confused of who is who.

Expenses: - Paul has kept a tight reign on costs. Where-ever possible he has timed his trips to Wellington to coincide with other government projects where his transport is paid. Our office is in Hamilton in RNZFB building. We now pay rent at a reduced market rate. This however has still made a big impact on our expenses. As a Board, we have used teleconferences rather than face to face meetings. These work, but I find them unsatisfactory as they are held at the end of a day when we are all tired and it takes us away from that special time with our families, so are very often hurried. The face to face meetings are now held at the BLENNZ campus in the "Bach" which was formally the principal's house. This gets a bit cramped with nine people, but it is a huge saving. We can self cater etc. We used to stay at the Bella Vista hotel, but the costs became prohibitive. I have to thank my Board colleagues and Paul for doing this. Paul and I have been known to sleep in the lounge on pull out beds. We are all volunteers giving up our time so this gets a bit hard, but shows our dedication.

Once again we have had to have a much scaled down conference and AGM due to the funding. Very few organizations will fund conferences through donations. To me conference is the essence of our PVI family. It is where we share our time, knowledge and experiences with people who do not judge but have walked the same path. It hurts me, as treasurer, to ask families to have to pay to come on conference. Thank you for working with us.

It may seem to you we have a lot of money in our bank account in reserves. We as a Board made a decision we wanted to have a minimum of six months running costs in reserve so if all our outside funding dried up we could survive for six months. We need to do this as responsible employers for our excellent EO Paul and for Lyn our Office Manager. The PVI car has 250,000 km on the clock and this may soon need to be replaced.

My highlight of the year was The Thorndon Project—"Stories to Tell". This project was thought up by David Heather and brainstormed with Paul and then funded by a grant from the Family and Community Services of the Ministry of Social Development. It was a real honour to get to Parliament for the opening, where I was left as a security guard by the government security to vet people coming in. Must have thought I was okay, so left me in charge. The following week saw the official launching of our CD. To see all the government officials, people from the Ministry of Education and Health there was amazing. The high regard in which they hold Paul Manning shows what a great job he is doing for PVI. He is constantly getting asked to go on government reference groups concerning children and disability.

If anybody knows of any organisation that could sponsor us please talk to Paul or any of the board members. We could include their name in our "Vision" Magazine.

Thank you to all you parents who have come today and may you and your families have a safe time over the next year.

Don Fairgray  
Treasurer 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 2 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, DeafBlind 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 SESTA. 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 10<sup>th</sup> 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 20<sup>th</sup> 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 2 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/ DeafBlind 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 6 meetings, 3 face to face and 3 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



Lean with me!

