

R.I.P. Julie Ingram

# VISION

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

**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.*

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## Thought of the Week - Courtesy of Steve Jobs

**You have to trust in something - your gut, destiny, life, karma, whatever. This approach has never let me down, and it has made all the difference in my life. I loved what I did. You've got to find what you love. And the only way to do great work is to love what you do. If you haven't found it yet, keep looking. Don't settle. As with all matters of the heart, you'll know when you find it. And, like any great relationship, it just gets better and better as the years roll on. So keep looking until you find it. Don't settle.**

**There is no reason not to follow your heart.**

**Your time is limited, so don't waste it living someone else's life. Don't be trapped by dogma - which is living with the results of other people's thinking. Don't let the noise of other's opinions drown out your own inner voice. And most important, have the courage to follow your heart and intuition. They somehow already know what you truly want to become. Everything else is secondary.**

**Steve Jobs, CEO of Apple Computer (1956 - 2011)**

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## From your National Office

Greetings fellow parents,

On the front cover are some very poignant words from Steve Jobs the recently deceased CEO of Apple Computers. Steve spoke about the love of ones work as this is what ultimately shapes us as human beings.... Fine words from those near death are often valued and held onto by those of us that are left behind; fine deeds are valued even more.

It is the deeds that I wish to comment upon especially when we have lost one of our most respected regional managers from BLENNZ. Sadly, we have said goodbye to a respected colleague and friend to many, Julie Ingram recently passed away with her family at her side. Our thoughts and prayers are with Julie's family - Steve her husband and her 3 sons.....To the parent community of the Gisborne area, we acknowledge your loss and also share in your grief. To the BLENNZ community, again, you have been in our thoughts and prayers.

Every now and then you meet and work with people that are inspirational, Julie was such a person, always, always there for our children and us as parents.... To Steve and family we thank you for sharing Julie with us, to the BLENNZ team in Gisborne, Kia Kaha, Kia Kaha, Kia Kaha....

Ka patai mai ki ahau, he aha te mea nui o te ao?  
Maaku e kii atu:

He Tangata, he Tangata, he Tangata

You ask me what is the greatest thing in the world?  
I will say:

It is people, it is people it is people

November has arrived, I am reminded it is only 4 days to Christmas..... The mere thought is alarming, this male is not ready for the Christmas madness. For the remainder of this year, from now until Christmas, I plan to keep it simple, not to say "Yes" all the time, take time out for myself and family and concentrate on loving the ones closest to me the most!

Yours truly has recently completed another 1/2 marathon. This time in Hamilton, a wonderful event and great health benefits for moi.... Someone else I know completed the Tour de Waikanae 25k tandem cycle event. Said son on rear of tandem was reported to be wearing an unofficial mouth-guard, whilst major sponsor Bendon Lycra was happy lead rider never made it to the podium. (Bright pink lycra body suit a size too small...not a pretty sight!)

I cannot help it, Rugby World Cup 2011, just amazing. We have gathered together as one nation in a fashion, I believe, we are all very proud. It is a wonderful opportunity to celebrate our different nationalities..... And haven't the Pacific Island nations shown us how to celebrate....love it. Go the All Blacks..... When talking to Australians, just mention, 4 more years!

The RNZFB Board meeting last month provided PVI with the opportunity to explain its concerns regarding a number of matters. The RNZFB Board has advised PVI to provide specific complaints to the Client Services Committee whereby complaints will be lodged in the "Issues Register". PVI is in the process of lodging a number of complaints. The nature of the complaints vary from RNZFB Fundraising, RNZFB Regional Office Closures, Consumer Group Funding and the AGM voting process.

With the PVI AGM taking place on the 19th November, we can report a healthy response from parents attending, thank you to those who are attending, to others who cannot attend we urge you to complete the Proxy form and fax to us or give to another parent who you know that is attending. It is important to us that we receive your proxy votes.....thanking you in anticipation...

Advocacy and Support work I have been involved in at a National level, include: - Working with the Ministry of Education with regards to a national complaints policy. This was born from PVI's response to the Review of Special Education last year. We have been asked to assist the MoE develop a complaints policy that works for parents as well as the MoE. Note this is not a complaints policy for schools which, I believe, will be dealt with separately. I am delighted to be working with the MoE in this fashion. There is a real sense of being able to deliver in a collaborative fashion, long may this continue...

I have been supporting parents in school related matters, as is the norm. I am finding a genuine attempt by schools to be seen to be more inclusive. However, it is frustrating, that I am also seeing issues of concern for parents that sadly we saw when our child was at primary school 15 years ago....Room for improvement, always room....Paul.

***"Being happy doesn't mean  
everything is perfect.  
It means you've decided to see beyond the  
imperfections."***



## The Many Lives of Hazel Bryan

In the most famous photo of the Civil Rights era, she was the face of white bigotry. You'll never believe what she did with the rest of her life.

It's the face of a white girl—she was only 15 years old, but everyone always thinks her older than that, and judges her accordingly—shouting at an equally familiar, iconic figure: a sole black school girl dressed immaculately in white, her mournful and frightened eyes hidden behind sunglasses, clutching her books and walking stoically away from Little Rock Central High School on Sept. 4, 1957—the date when, in many ways, desegregation first hit the South where it hurt.

It's all in that white girl's face, or so it has always appeared. In those raging eyes and clenched teeth is the hatred and contempt for an entire race, and the fury of a civilization fighting tenaciously to preserve its age-old, bigoted way of life. You know what the white girl's saying, but you can't print it all: commands to get out and go home—"home" being the place from which her forebears had been dragged in chains centuries earlier. What that white girl was actually doing that day was more grabbing attention for herself than making any statement of deep conviction doesn't really matter. Of anyone with *that* face, you simply assume the worst. You also assume she is beyond redemption, especially if, symbolically, she is more useful as is than further understood or evolved.

So how is it that fifty-five years later, it is this same white girl—even more than the black girl—who feels aggrieved, who considers herself the victim of intolerance, who has retreated into embittered sadness? How can it be that she, who was so prominent at the joyous 40<sup>th</sup> anniversary of the events in Little Rock, celebrated by President Bill Clinton among many others, was invisible at the 50<sup>th</sup>, and ever since?

The black girl is [Elizabeth Eckford](#) of the [Little Rock Nine](#). Moments earlier, she'd tried to enter Central High School, only to be repeatedly rebuffed by soldiers from the Arkansas National Guard placed there by Gov. Orval Faubus. A mob baying at her heels, Elizabeth is making her way, fearfully but determinately, toward what she hoped would be the relative safety of the bus stop a block away.

*The face belongs to Hazel Bryan. Hazel, the daughter of a disabled war veteran, was largely apolitical, even on matters of race; while sharing the prejudices of her parents, she cared far more about dancing and dating. Being in that crowd that morning, making a ruckus, outshouting all of her friends, was a way of getting noticed, and far more exciting than going into class. She'd thought nothing would come of what she'd done, and nothing ever would have had she not been captured in mid-epithet by [Will Counts](#), a young photographer for the *Arkansas Democrat*.*



If anyone in the picture, which reverberated throughout the world that day and in history books ever since, should feel aggrieved, it's of course Elizabeth Eckford. What Counts had captured both symbolized and anticipated the ordeals that Elizabeth, a girl of unusual sensitivity and intelligence, would face in her lifetime.

First came the hellish year she and other black students endured inside Central, and then decades in which the trauma from that experience, plus prejudice, poverty, family tragedy, and her own demons kept her from realizing her extraordinary potential.

With enormous courage and resiliency, Elizabeth ultimately made a life for herself and has largely come to peace with her past. Paradoxically, it's been Hazel, who has led a life of far greater financial and familial security, who now feels wounded and angry. Someone who once embodied racial intolerance feels victimized by another form of prejudice, in which good deeds go unappreciated, forgiveness cannot possibly be won, and public statements of contrition breed only resentment and ridicule.

Concerned over her sudden notoriety, only days after the infamous photograph appeared, Hazel's parents transferred her from Central to a rural high school closer to home. She never spent a day in school with the Little Rock Nine and played no part in the horrors to which administrators, either lax or actually sympathetic to a small group of segregationist troublemakers, allowed them to be subjected. And she left her new school at 17, got married, and began a family.

But Hazel Bryan Massery was curious, and reflective. Tuning in her primitive Philco with the rabbit ears her father had bought her, she heard the speeches of Dr. Martin Luther King Jr., and saw those black protesters getting hot coffee and ketchup poured on their heads at segregated lunch counters or being routed by fire hoses and German shepherds.

## The Many Lives of Hazel Bryan (cont.)

Such scenes brought home to her the reality of racial hatred, and of her own small but conspicuous contribution to it. One day, she realized, her children would learn that that snarling girl in their history books was their mother. She realized she had an account to settle.

Sometime in 1962 or 1963—no cameras recorded the scene, and she didn't mark anything down—Hazel, sitting in the trailer in rural Little Rock in which she and her family now lived, picked up the Little Rock directory, and looked under "Eckford." Then, without telling her husband or pastor or anyone else, she dialed the number. Between sobs, she told Elizabeth that she was *that* girl, and how sorry she was. Elizabeth was gracious. The conversation lasted a minute, if that. In the South, in the '60s, how much more did a white girl and a black girl have to say to one another?

Secretly, Hazel always hoped some reporter would track her down and write about how she'd changed. But it didn't happen on its own, and she did nothing to make it happen. Instead, again and again, there was *the* picture. Anniversary after anniversary, Martin Luther King Day after Martin Luther King Day, Black History Month after Black History Month, it just kept popping up. The world of race relations was changing, but to the world, she never did.

Then, quietly, Elizabeth and Hazel discovered something quite miraculous: They actually liked each other. For all their differences—Elizabeth was better-read, Hazel's life far better-balanced—they shared a good deal. Both were introspective, skeptical, a bit isolated; neither fit in anywhere, including in their own families. They visited one another's homes, took trips together, spoke to schools and civic groups. In the process, Hazel helped pull Elizabeth out of her shell, then to blossom. Unemployed, on mental health disability for years, Elizabeth soon returned to work, as a probation officer for a local judge. Two years after they'd first met, the pair even appeared on *Oprah*.

Winfrey hadn't bothered hiding her incredulity, even disdain, that day: Of all people, *these two* were now friends? But as rude as both felt her to have been, she'd been on to something. The improbable relationship had already begun to unravel.

A student of, and stickler for, history, Elizabeth looked for—and, she thought, spotted—holes in Hazel's story. How, for instance, could Hazel have undertaken something so cruel so casually, then remembered so little about it afterward? And why, after all these years, did she absolve her parents from any blame? At

their joint appearances, Elizabeth could treat Hazel impatiently, peremptorily. Meantime, others in the Little Rock Nine either shunned Hazel or complained of her presence at various commemorations.

But resentment came as well from whites, particularly whites who'd attended Central, particularly those from better families, who'd thought that, even by always looking the other way, they'd done absolutely nothing wrong during those dark days and, truth be told, considered Hazel and her ilk "white trash."

Forty years earlier she'd given them all a black eye; now, she was back, more conspicuous, and embarrassing, than ever. At a reunion she foolishly, or naively, attended, she felt their cold shoulder, and could hear their snickers. None of *them* had ever apologized for anything they'd done or not done, and, as far as Hazel could tell, they'd been none the worse for their silence.

Ultimately, it grew too much for Hazel. She cut off ties with Elizabeth—for her, Sept. 11, 2011 marked another anniversary: 10 years had passed since they'd last spoken—and stopped making public appearances with her. Her interviews with me—granted only with great reluctance—will, she says, be her last. When I asked the two women to pose together one last time (Elizabeth turned 70 last Tuesday; Hazel will in January) Elizabeth agreed; Hazel would not. Hazel was poised to vote for Obama in 2008; after all, even her own mother did. But so deep was her hurt that she found some excuse not to.

So the famous photograph of 1957 takes on additional meaning: the continuing chasm between the races and the great difficulty, even among people of good will, to pull off real racial reconciliation. But shuttling back and forth between them, I could see that for all their harsh words—over the past decade, they've only dug in their heels—they still missed one another. Each, I noticed, teared up at references to the other. Perhaps, when no one is looking—or taking any pictures—they'll yet come together again. And if they can, maybe, so too, can we.

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***There is a connection in this story that we as parents of disabled children understand. Do we not long for the same level of equality for our children and on the surface it is there, but scratch underneath and our children and disabled adults live in a world designed by and for sighted people. One day, one day disabled children/adults will receive services as of right, not on perceived need of the non disabled.....***



## KICKSTART—an option for your child?

# Kickstart Students Climb The Harbour Bridge

By Emily Sanson

What a wonderful opportunity it was to be able to climb to the top of the Auckland Harbour Bridge. This was a real challenge for some who don't particularly like heights and it was a long walk for some who find this a difficulty. When we arrived at the destination we had to put on certain equipment that was needed for the climb.

It was funny when I tried to put my suit on because I put my foot through the arm hole, no wonder it was hard to get on.

We were very lucky; the day was reasonable, not hot or too cold. We were wearing protective clothing, but it was very windy. The wind was a difficulty because it pushed some people along, particularly me, I couldn't slow down. Our harness attached us to the wire rope for the climb so we did not get blown off.

We wore protective helmets, and were given a warning about low beams...but these beams were well padded for the climbers' protection.

The steps changed, some were narrow, some were wide, some were up, some were down, some were deep, some were shallow, some were smooth and some were very, very uneven but we communicated well so we were well prepared and did not stumble.

We were lucky to be in a group by ourselves. This meant we could travel at our own pace and stop when necessary.

At each stop our guide gave us information about Auckland and the history of the Bridge.

One student said that he enjoyed the climb because it was good exercise for him and at the top we got to wave at cars and honk at trucks to make them toot.

What he found incredible was, that under the very centre of the bridge was about the length of the Sky Tower. It was an expensive outing but if he had the chance to do this again he would.

Another student said she was trying to stay calm before she got up, but the nerves just kept getting stronger. She hadn't been that close to moving cars in a while, she tried not to look there and tried to smile when the photos were taken so she didn't look

nervous. She was proud that she did it even though she was scared because it made her feel stronger inside.

Just as we left some Scotsmen were preparing to Bungee in their kilts!

Our photo shows Kickstart students and staff at the top of the Bridge. The Sky Tower can be seen in the distance.



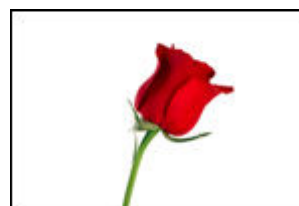
### PVI Response:

Kickstart is another service/programme offered by the BLENNZ network. It is designed for students who need to learn more independent life skills. It involves moving from Home into a hostel accommodation on the BLENNZ campus whereby students cook for themselves, manage their own affairs and attend entry level tertiary study courses or something similar.

Over the years, I have witnessed huge growth in the students who attend. The getting away from home and having to manage is huge and makes them grow-up real quickly!

I can thoroughly recommend Kickstart.

For further information about Kickstart contact Jude Shelley. email: [jude.shelley@blennz.school.nz](mailto:jude.shelley@blennz.school.nz)



"Never worry about numbers.  
Help one person at a time,  
and always start with  
the person nearest you."  
**Mother Teresa**



# **PARENTS OF VISION IMPAIRED (NZ) – OUR VISION / OUR DREAM**

## **WHO ARE WE?**

Parents of Vision Impaired (N.Z.) Incorporated simply known as "PVI"  
Since its inception in October 1984 PVI has grown to its present size of over 1,600 parents nationwide.  
PVI enrolls parents who have blind or vision impaired children.

## **PURPOSES OF PVI**

To empower parents and whanau to support their blind, deaf blind and vision impaired children.  
To improve the health, welfare, education and social opportunities of blind and vision impaired children.  
To benefit the children and whanau of vision impaired children within New Zealand.  
To promote, develop and maintain a nationwide support network.  
To promote and provide ongoing communication for parents and parent support groups of vision impaired children.  
To foster communication and co-ordination of services between PVI, agencies and other community groups.  
To be proactive in all areas and concerns related to vision impaired children and their family/whanau.  
The purpose of PVI is to be beneficial to the Community

## **OUR WHAKATAUAKI/PROVERB:**

*Kia hora te marino, Kia whakapapa pounamu te moana,  
Kia tere te karohirohi, I mau I te herenga, Kia tau te rangimari e.*

*May the calm always be at your side, May the sea glisten like pounamu, May the shimmer of summer dance across your path, May you always find peace*

## **OUR MISSION**

Supporting and Empowering Parents and Whanau

## **OUR VALUES**

PVI believes:

That visual impaired/blind and the families/whanau have the right to the same dreams,

opportunities and safeguards as other citizens.

That all people are unique and different and each is capable of great things.

That all communities and society can develop to fully include all visually impaired/blind people.

## **OUR GUIDING PRINCIPALS**

We develop and grow to better meet the needs of our membership

Recognising the Treaty of Waitangi as this country's founding document

## **COMMUNITY/FAMILY/INDIVIDUAL**

All children & family/whanau are included  
Rights are respected & different needs are accommodated  
Equity reaches across gender, culture, ethnicity and disability

## **INFORMATION**

Information enables families/whanau to take control over their own lives  
Information leads to informed choice  
Families right to integrity, and confidentiality is protected  
Information is culturally appropriate

## **ACCESS (the built environment & universal design)**

Everyone can access buildings and transport safely  
The built environment enhances peoples participation  
Access to parks, resources and the natural environment is continually being enhanced

## **COMMUNITY DEVELOPMENT**

The diversity across vision impairment is understood  
Vision impaired awareness is part of the training of everybody working with vision impaired children/families  
The community says "we value blind and vision impaired/ children"

# PARENTS OF VISION IMPAIRED (NZ) INC

## Strategic Planning Document 2010-2015

STRATEGY	ACTION STEP	TIME FRAME	EVALUATION
<p><b>1. To support parents/whanau so that they are empowered to support their children</b></p>	<p>Training Provide social and emotional support to parents Advocacy to provide and ensure equal opportunities</p>	<p>On-going Quarterly reporting</p>	<p>Feedback via survey Board Report post Conference Face to Face Multi-media</p>
<p><b>2. To grow PVI</b></p>	<p>To develop an comprehensive/ effective parent base Ensure a comprehensive list/ record of parents is maintained PVI is effective at Local/Regional/ National levels</p>	<p>Ongoing Quarterly reporting</p>	<p>Parents have taken up training opportunities. Training records kept and a evaluation of training analyzed. Phone Tree system is operating. Regional Reps have up to date contact lists for their area Database demonstrates increased membership showing up to date information. Demonstrate Regional Rep attendance at /Board training. Training records kept and a evaluation of training analyzed. Parents attending a local event via attendance records. Results Based Outcomes process</p>
<p><b>3. Building a Healthy Community</b></p>	<p>Effective communication with all parents across all cultures within NZ To best utilise all forms of communication and technology Effective Relationships with: PVI Parents, PVI Regional Representatives &amp; Board members, Government, NGOs, BLENNZ, RNZFB/Sector groups</p>	<p>Ongoing quarterly reporting</p>	<p>Parent survey and anecdotal feedback, Active membership showing an increase in parents from a variety of cultures Demonstrate and grow relationships with other cultural organisations Demonstrate multi media formats of information to parents i.e.: Vision website, face to face Telephone, local get-to-gethers, regional meetings, DVD Board development, Short survey to allied organisations, Project work carried out by PVI in collaboration with other organisations to reach common goals Level of invitations received to attend meetings of other organisations.</p>
<p><b>4. Moving Forward together</b></p>	<p>To ensure the PVI structure and performance is meeting the needs of its members Operate within a sustainable funding model</p>		<p>Parent Survey Small focus group meetings of parents to give feedback Performance appraisal of Board, EO and staff  Financial accounts show fiscal responsibility</p>

# PVI Operational Plan

STRATEGY	STRATEGIC TASKS	PERSON(S) RESPONSIBLE	Priority
<b>Strategy 1</b> <b>To support parents/whanau</b> <b>so that they are empowered to support their children</b>	Governance reporting: Completion of SP Completion of OP Completion of Policies & Procedures	Judith, Riripeti, EO	1
	Training: To identify training opportunities for 'gaps' in current parent training from information already gathered	<i>E O and Board</i>	2
	To develop a training strategy acknowledging the various levels		2
	Advocacy: To continue to support parents and whanau and act as advocate		On-going
<b>Strategy 2</b> <b>To grow PVI</b>	Governance: Grow Regional Reps & Board positions to a full compliment.	<i>EO and Chair</i>	2
	Encourage active participation at Regional & National Training	<i>EO and Chair</i>	2
	Profile: 1 local event for parents happening per year.	Regional Reps & Board	2
	Develop and maintain effective parent database	EO	2
	Sufficient staff time to maintain and update data base	EO	3
	Up-date pamphlets for distribution to Regional Reps & Board	EO & Board	3
	2 media articles per annum about PVI and its role in local media		3
<b>Strategy 3</b> <b>Building a Healthy Community</b>	Communication & Knowledge: Build and maintain external relationships, ie: NZ Blind Community Consortium (funding options) Blind & Low Vision Education Network NZ (Charter consultation)	EO & Chair	Quarterly Reporting of external Relationships to the Board 1
	To build & maintain health relationships with parents/whanau, hapu and Iwi Vision magazine	EO	
	Website & pamphlet information available in English, Te Reo and Pacific Island?	EO	3
	National Conference/AGM	EO	1
	Board Development	EO & Board	2
	SPEVI		2
	Pacific Forum Explore multi-media options Link on website to translation opportunities for other languages	EO	3
<b>Strategy 4</b> <b>Moving forward together</b>	Growth & Succession Planning: To ensure that PVI continues to meet the needs of parents/whanau, hapu, Iwi:	EO & sub-committee (Adriane/Don)	1
	Ensure a sustainable funding model	EO & sub-committee (Riripeti/Judith)	1
	Develop surveys, evaluation and appraisal templates	EO, Board and Regional Reps	2
	Identify opportunities for small group meetings ie At local parent trainings		2
	Identify external facilitators to complete Board Appraisals Appraisal of EO EO to carry out appraisal on staff as required	Chair EO/facilitator	2

Priority 1 = 1<sup>st</sup> quarter Progress/completion  
 Priority 2 = 2<sup>nd</sup> quarter Progress/completion

Priority 3 = 3<sup>rd</sup> quarter Progress/completion  
 Priority 4 = 4<sup>th</sup> quarter Progress/completion



## Support for our Teenagers

Dear Parents, if you have teenagers who are vision impaired/blind then this article you might get them to read....

Zane, a vision impaired young man, has developed a place for youth to talk in the Facebook - Retina Youth. In this youth section it is totally open for discussion..... Zane can also be contacted on zane\_b@live.com Zane is willing to feature young people with their stories, subject to approval of course. Perhaps your teenagers stories can inspire others to come forward and share....

There are other groups in existence who meet regularly to share information, support and practical knowhow about managing everyday tasks with low vision. These groups are cool for people of any age but a youth presence makes them totally fun. There are also free snacks....

The Kapiti VIPs = Visually Impaired Persons meet monthly at 1.30pm on the 3rd Monday at the Kapiti Community Centre in Paraparaumu. If you would like to know more phone Heather, 04 298 7304.

Waikanae VIPs meet 1.00pm first Monday of the month at the Pop-in Centre, Mahara Place. For more information phone Sue on 04 293 5174.

The Dunedin VIPs meet at 1.30pm on the 4th Wednesday of the month, for further information phone Linley on 03 487 7686 or ljhood@ihug.co.nz

This is an opportunity for the Teenagers/young adults to communicate and meet and greet on their terms not ours as parents or sighted adults....

Social contacts are everything, social contacts that understand and accept their vision loss is something special....



## PVI Facebook and Fathers!

PVI does operate a closed "facebook" called Parents of Vision Impaired NZ. Here parents can talk knowing that they are safe to do so.

As your E.O., I visit the site occasionally, as others younger than I are more comfortable with this format of communicating.

What I witness when I do go online, is the wonderful support and ideas that are being shared amongst mothers. I have yet to hear from a Dad on the PVI facebook....I wonder why?

•Some men, about 90% perhaps do not wish to be involved in what is perceived as a predominantly female chat room.....

•Perhaps Men do not have the time or inclination to become involved with an online support group as they do not trust this medium. Maybe, they prefer the face to face etc....

•Others might feel, if we are going to talk then I would prefer to talk to my wife/partner first before engaging with another Dad

For those who might like to explore this option then perhaps you might like us to set-up a Dad's facebook page and see what happens!!!

### PVI AGM

For those parents living locally you are reminded of the Parents of Vision Impaired AGM to be held at 11.30am at the Bella Vista Express Hotel, 14 Airport drive, Airport Oaks, Auckland Airport, on Saturday 19 November 2012. Please advise the national Office of attendance by 16 November.

### PVI Proxy Voting Form

If you cannot attend:

**Please send/fax Proxy voting form to PVI before the 18 November, 2012.**

## **International Conference in Complex Learning Difficulties and Disabilities 4th—5th April 2012 Hamilton**

**For information and registrations go to:  
[www.positivepath.co.nz](http://www.positivepath.co.nz)**

## Greetings from the Pacific Disability Forum!

In the Pacific, the greatest barrier to our young people with disabilities face is discrimination and social isolation. Forum Leader should also consider youths with disabilities in the youth programs they have set out making sure that the programs are inclusive as well as accessible. Globally, the World Bank has estimated some 180 million young people between the ages of 10-24 living with a physical, sensory, intellectual or mental health disability. The vast majority of these young people, some 150 million (80%) live in the developing world and as such are among the poorest and most marginalised of the entire world's young people.

Leaders must ensure that the lifecycle of indignity and prejudice faced by youth with disabilities is removed. Legislation must be put in place to ensure inclusiveness for all, where youths are involved. Where different cultural, linguistic and religious traditions are evident, youths with disabilities are to be included in whatever services and programme that exist. Specific policies, programmes and initiatives for youth with disabilities will vary from one culture to the next but the basic question of whether young people with disability have the same right to education, employment, social participation and self-determination as their non-disabled peers, offers a starting point for assessing the economic and social inclusion of adolescents and young adults in a broader cross-cultural framework as common in the Pacific.

Pacific Disability Forum in its Strategic Plan 2011 – 2016, has set the foundation by gathering youths with disabilities from a few Pacific islands countries in the last 3 days to hear from them and work with them on a Strategic Plan for Youth with Disabilities in the Pacific for the next 5 years. This will build the momentum in pushing for inclusiveness for our youths with disabilities in Government Policies and legislations in by the year 2016. PDF believes that their existence and the well-being of society as a whole will be much richer if these young people are allowed to develop to their full potential.

In the Pacific, families living with a disability face a lot of challenges and often need support and education in order to create a lifestyle that promotes the overall health, wellbeing and personal growth of everyone involved.

As parents we need to take some important steps towards creating a productive and safe atmosphere, in which this lifestyle can be built. It is important to have the facts when raising a child with disabilities.

Asking or reading credible information provided by medical professionals is vital. It would also be beneficial to look and speak with other parents living with a similar child in the community. They can often offer valuable insight into the best ways to integrate treatments, therapies and necessary  
L i f e s t y l e c h a n g e s .

Although many families in the Pacific do not have family physicians, it is essential to understand that children with disabilities need more specific assistance from specialists as well. It is critical to find a doctor who communicates openly, listens, and is prepared to work together for the welfare of your child. In addition, the nurses, physician assistants and administrative staff should also make up the people you feel comfortable and trusting in your child's well being.

Education is crucial when it comes to the growth of any child and children with disabilities need physical and intellectual encouragement to smooth the progress of proper brain development. Choosing special education or school program is a challenging task. There are many details to consider such as budget, location, daily schedule and more. It may take time to review all these options, as well as complete application forms, so be sure the process is not rushed.

PDF believes that a reliable, trustworthy support is essential for any family having the challenge of living day to day with a disability. There is nothing more valuable than having other parents and children to share ideas, treatments and experiences with. There are times when encouragement, inspiration and hope will come from those around you that can relate to your situation.



## MoH — Respite Care in Auckland not delivering!

Wendy Duff's 17-year-old son, Elliott, has severe autism. He's big, he's strong and caring for him at home is full on.

For the Duffs, having out-of-home respite care for Elliott is crucial.

"We're tired, we're stressed and we need to have that break," says Mrs Duff.

"It's nice to be able to relax in your own home.

"And Elliott enjoys respite as well, mixing with others and going out - it broadens his horizons."

So six nights a month Elliott stays at a Spectrum Care house for children, based in Mangere.

But in April Elliott will turn 18 and his family's respite options will suddenly diminish.

That's because Auckland's two respite homes for 17- to 65-year-olds have closed waiting-lists and an extension period for teens such as Elliott is coming to an end.

Mrs Duff is president of Autism New Zealand and last October took part in a meeting between representatives from the Ministry of Health and families worried that future respite options for their teenagers were severely limited.

"From that meeting last October, the Ministry had their eyes opened to the fact many families had their children turning 17 soon," she says. "The Ministry agreed with Spectrum Care to allow our children to continue [receiving care at facilities for children] up to January 2012 or until they turned 18, whichever came first."

She says both a contingency plan from January 2012 and a promised Ministry of Health review of the respite care sector have been slow in coming. "Sometimes we survive from respite to respite. Something has to happen. Come January, if our children don't get respite we may be forced to put them in residential care and that's the last thing we want to do."

Not one to give up the fight, Mrs Duff is working to bring the issue before the ministry once again.

"I knew there were families out there who had fallen out of the respite system so I started to email around my networks," she says.

"There have already been about 50 families respond, some saying they don't have any respite, others have a child nearing 17 and are afraid they can't live without respite."

This flood of responses has led to a forum to be hosted by the Parent and Family Resource Centre and attended by representatives from the Families Commission, Autism New Zealand, the Ministry of Health and needs assessment agency Taikura Trust. "This is an opportunity for people to stand up and speak," says

Mrs Duff. "There will be some angry parents there."

The director of the Parent and Family Resource Centre, Lisa Martin, says anecdotal evidence shows that lack of respite services puts enormous pressure on families.

"We repeatedly hear from families that they do not know some services exist, do not know how to access them, or do not manage to secure the services they require," she says.

"This places incredible pressure on families, sometimes resulting in family separations."

She says the forum will provide opportunities to ask questions and give written feedback on specific issues.

"We will collate the data and stories collected to assist our drive for increased supports for this vulnerable group of families."

The Ministry of Health told The Aucklander details of the Respite Review are being finalised and at this stage it is likely to start early next year.

The ministry says it is working with children's respite providers on a plan for future respite care for teenagers in Auckland. It is expected to be finalised in the next few weeks.

### One year on

In November last year The Aucklander examined the respite care shortage for over 17-year-olds and met Janine Alexander and her son Steven, now 17. Mrs Alexander initiated last year's meeting with the Ministry of Health which led to Steven and other teens getting an extra year of out-of-home respite.

When we speak she is tentatively positive about progress. "I got a letter from Spectrum today to say they were in negotiations with the Ministry and that Steven may get another extension of two years.

"It's a huge reprieve but of course it limits other referrals coming into the Spectrum house and I feel quite guilty about it."

She says there is an "absolute need" for more respite facilities in Auckland and for her family the out-of-home model is vital. "Steven learns as much from being there as we benefit from the break. It just means so much."

### RESPITE CARE MEETING

The forum on Respite and other Ministry of Health funded Disability Support Services will take place November 2, 6 - 8.30pm at CCS Disability Action, 14 Erson Ave, Royal Oak. This forum is open to the public, those with disabilities, family members, siblings, and related professionals.

Write to us [letters@theaucklander.co.nz](mailto:letters@theaucklander.co.nz)  
Story ideas to [editor@theaucklander.co.nz](mailto:editor@theaucklander.co.nz)

# **RNZFB Teenagers' Abel Tasman National Park Kayaking Trip**



**What:** A guided Sea Kayaking Camping Trip through the Abel Tasman National Park.

**When:** Monday 23<sup>rd</sup> January – Friday 27<sup>th</sup> January, 2012

**Where:** An adventure through the remote areas of Abel Tasman National Park exploring the secluded beaches, coastal forests and wildlife of the park.

**Who:** Blind and Vision impaired RNZFB members, aged 14 – 18 years. Please note we can only take up to 10 participants

***In order to be selected you must fit the following criteria:***

- Be in good health and physically active/fit
- You must be independent in terms of self care
- You must be capable of sustained paddling
- You must be confident in the water with basic swimming skills.
- Be a good team player

**Cost:** The subsidized fee is \$150 per participant. This includes transport, food, activity, and accommodation costs

Applications will close **Wednesday 30<sup>th</sup> November.**  
**NO LATE APPLICATIONS WILL BE ACCEPTED**

***Please contact Sarah Jones on 03 375 4327 or [sjones@rnzfb.org.nz](mailto:sjones@rnzfb.org.nz) for any other details***

## For your benefit.....

We are pleased to let you know that applications for 2012 are now being sought by the **Oppenheim Tertiary Trust**.

This Trust was founded by Dr and Mrs Oppenheim in November 1989. The purpose of the Trust is to provide assistance to blind and partially sighted people who are presently undergoing or are about to enter tertiary education.

The Trust defines tertiary education as courses of study leading to a degree or recognised vocational qualification.

RNZFB members wishing to apply must complete the [Oppenheim Tertiary Trust application form](#) in full and supply supporting material and letters. Please contact your local RNZFB office for further details.

The closing date for applications is **Wednesday 25 January 2012**. (Late applications will not be accepted.) Trustees will meet in early February 2012 with disbursements to successful applicants by mid February 2012.

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### *A FOLLOW-UP OF "WELCOME TO HOLLAND" - FROM VISION ISSUE 87*

## **CELEBRATING HOLLAND – I'M HOME**

I have been in Holland for over a decade now and 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 when I first landed in Holland. I remember clearly my shock, my fear, my anger, and the pain and uncertainty. In those first few years I tried to get back to Italy, my planned destination, 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 changed, like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travellers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many encouraged me; many taught me to open my eyes to the wonder and gifts to behold in this new land. I discovered a community of caring - Holland wasn't so bad!

I think that Holland is used to wayward travellers like me and grew to become a land of hospitality, reaching out to welcome, assist and support newcomers. Over the years, I have wondered what life would have been like if I had 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?

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. 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 traveller and discovered that it doesn't matter where you land; what is 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!

Hi Paul. Over the last few days I have received in the mail two letters from the RNZFB, both of which are concerning me.

The first was a further request to participate in their fundraising efforts by doing some baking and then taking donations for it from the public. I feel this is a very unfair method of fundraising, and a sneaky way of "user pays". Those most likely to be collectors are normally people affected by vision loss in some way. Therefore, the Foundation is actually asking those people to not only give up their time to collect donations, but to also pay for the materials needed to produce the goods to offer in exchange for the donation. I personally find this rather insulting, and I feel almost "used".

The second letter was a request for donations. This letter bothered me on two counts,... the amount of money asked for, and the use of a child to tug at the heartstrings.

The minimum donation was listed as \$125. Quite a large sum in these tough financial times, and it doesn't offer the donor any option to give a lesser amount. In my opinion that will deter anyone from sending a smaller amount, therefore they Foundation dips out altogether. What happened to the idea that even a small donation mattered. Are the \$10's and \$20's not wanted?

And I find the use of a child in the advertising to be simply disgusting, when the Foundation are currently cutting the funding to the very group that provides the most support for those children and their parents,.....PVI. This is yet another slap in the face to all those parents who value the advocacy and support PVI have given over the years, only to now be reduced to providing advertising material and do baking. Sorry, but the Foundation has provided very little support to my family over the last 18 years, and yet PVI are there no matter what, every single time. The RNZFB has consistently struggled to provide many of the services my child has needed, and is funded for through ORRS money, yet the brochure makes it sound as though the kids every need is immediately fulfilled by the Foundation alone.

Once again, I feel the RNZFB has totally missed the mark when it comes to having any clues what is important to members and their families, and has left us feeling used and almost abused.

Paul, if you have a voice that will be heard by the Foundation, please pass this on to them, as once again, it is PVI we turn to, not the RNZFB....



"Remember there's no such thing as a small act of kindness. Every act creates a ripple with no logical end."  
- **Scott Adams**

Hey Paul,

This week's guest on the Cooking Without Looking Show was our very own Natalie Te Paa!

Find out what she'd make if the PM came to her place for afternoon tea!

In this delightful interview I got to uncover what makes Natalie tick and what flows through her veins .....

Music....Music.....Music....

The Cooking Without Looking Show streams live on [www.oar.org.nz](http://www.oar.org.nz) each Wednesday at 1 pm, an hour of food that comes in cans not cannots!

We transcribe recipes into braille, do a live Cooking Without Looking demonstration and our guest tells us what they would make if the PM came to their place for afternoon tea!

All music on the show is from blind musicians only – nationally and internationally!

If you want to download a podcast of the show then go to [www.oar.org.nz/podcast](http://www.oar.org.nz/podcast) You'll find it all there!

Kia Makona – Bon Appetit!

Hugs J

**"that blind woman"**  
**Julie Woods B. Comm.**  
**Inspirational Speaker, Author and**  
**Radio Show Host!!**

## Websites and info.....

**www.pvi.org.nz** This is our website, check it out!

**www.blennz.school.nz** The new BLENNZ website, take a look, well worth the journey!

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

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

**www.humanware.com** Excellent products available for both Low Vision and Blind users.

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

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

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

**www.aniridia.org:** Aniridia support

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

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

**www.rnzfb.org.nz** The website of the Royal New Zealand Foundation of the Blind.

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

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

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

**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**.

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

**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

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

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

**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.

**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.

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

Microphthalmia Anophthalmia.

**www.familytimes.co.nz** a newspaper produced quarterly, ChCh and Auck based, well worth a read.

[www.parentsvoice.org.nz](http://www.parentsvoice.org.nz) and/ or 'like' Parents Voice on Facebook .

**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**.

**The Koru Care:** This charity is linked to Air N Z. They specialise in taking children with Special Needs to Disneyland/Gold Coast Australia. Contact **09 523 2456** to see if your child qualifies. There are also contacts at Wellington and Christchurch offices of Air New Zealand.

[www.yesdisability.org.nz](http://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.

**Pacific Vision:** email Barry at barry@pvi.co. 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:** atolley@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
- Taranaki
- Manawatu
- Otago
- Southland.

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. National Training is provided FREE normally 1 weekend per year. Support seminars will more than likely be provided in a community near where you live. If you have a little time to give and wish to further support us please contact **Paul: 0800 312 019**

## Your PVI Board

**Chair: Lower North Island Representative:**

Mr. Kevin Beaver: 04 589 3719 k.beaver@clear.net.nz

**Upper S.I. Representative:**

Mr. Grant Davies: dandgdavies@xtra.co.nz

**Treasurer: Central N.I. Representative:**

Mr. D Fairgray: 027 286 7798

**Lower South Island Representative:**

Ms. Judith Hyslop: 03 476 6666

judithhyslop@xtra.co.nz

**Upper North Island Representatives:**

Mrs. Kim Lewin: 094221012 lewinfamily@xtra.co.nz

Mr. K. Singh: 027 320 6317 kam\_mit@hotmail.com

**Anywhere in N.Z. Representative:**

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

**Tangata Whenua Representatives:**

Ms. Riripeti Paine: 06 838 3949

Mrs. Kitty Tuari: 09 372 5453 ktuari@gmail.com

**Pacific Island Representative: Vacant**

Return Address:

Parents of Vision Impaired NZ Inc

PO Box 366

Waikato Mail Centre



## Regional Support Parent Contacts

<b>Dargaville:</b>	Gaynor Edgar	09 439 4439	<b>Napier:</b>	Lou Halbert	06 845 4706
<b>Wellsford:</b>	Kim Lewin	09 422 1012	<b>Taranaki:</b>	<b>Vacancy please Apply</b>	
<b>North Harbour:</b>	Linda Moore Carter	09 442 1330	<b>Wanganui:</b>	Amanda & Rex Van Elswijk 06 345 0327	
<b>Auck. Central:</b>	<b>Vacancy please apply</b>		<b>Manawatu:</b>	<b>Vacancy please apply</b>	
<b>Auck. South:</b>	Kawaljeet Singh	09 299 8028	<b>Wellington:</b>	Christine Pask	04 527 7585
<b>Auck. West:</b>	Paulette & Rodney Francis	09 835 1232	<b>Kapiti</b>	David & Rhonda Heather	04 203 6539
<b>Auck. East:</b>	Kawaljeet Singh	09 299 8028	<b>Nelson:</b>	Adrian Secker	027 201 1028
	Tirzah Shepherd	09 530 9539		Trudy Perrett	03 544 6641
<b>Hamilton:</b>	Maxine Jeffery	07 853 7006	<b>Christchurch:</b>	Andrea Lamont	03 980 1566
<b>Tauranga:</b>	Linda & Don Fairgray	027 286 7798	<b>Oamaru:</b>	Pat Fox	03 434 3499
<b>Rotorua:</b>	Lex & Helen Craig	07 349 3191	<b>Alexandra</b>	Sarah Hinton	03 449 2414
<b>Wairoa:</b>	Riripeti Paine	06 838 3949	<b>Invercargill:</b>	Kim Hartley	03 217 1906