

VISION

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



PVI's Whakatauaki/Proverb:

*Kia hora te marino, Kia whakapapa paonamu 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.*



Issue 87

August/September 2011

**You are invited to attend the Annual General Meeting
of Parents of Vision Impaired (N.Z.) Inc.
to be held on Saturday, 19th November, 2011, at the
Bella Vista Express Hotel, 14 Airpark Drive, Auckland Oaks,
Auckland Airport, Auckland at 11.30am**



Last year's AGM and Conference, Wellington

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From Your National Office

Greetings fellow parents,
The Rugby World Cup has finally arrived and so has spring. Almost forgotten are the severe cold spells we all endured last month. We could hear the mutterings of "harden up" from the south, here in Hamilton!

We had parents snowed in, who could not attend work, children the same, social networking went into overload, some of the email traffic I received was great, parents I had not heard of for some time made the effort, it was great!

The adjacent squirrel as photographed in Pat Fox's back yard.... Yeah Right!



RNZFB Board Elections, your entitlement and your responsibility:

The Royal New Zealand Foundation of the Blind (RNZFB) Board elections 2011 are to take place in October. Parents whose child meets the RNZFB membership criteria and is aged 0–16 are able to vote. If eligible, you will be receiving regular information from the RNZFB like the "Outlook" publication, and soon you will be receiving the voting forms and list of candidates for the vacant board positions. This year there are 3 positions up for re-election and P.V.I. needs your support.

The PVI Board has decided to support David Heather as a candidate for these elections. David brings a long history of association and support with the RNZFB and PVI. David was a founding member of Parents of Vision Impaired (NZ), and has continued his interest and membership until the present. David's biography will be sent to you (along with other candidates') with the voting papers. There may well be other candidates for whom you may wish to vote. To ensure your votes have maximum impact you might wish to consider strategic voting and vote only for the candidates you wish to support and not necessarily for the maximum number possible.

So why has David decided to become part of the RNZFB Board of Directors at this point in time. David has indicated that he wishes to be part of a Governance team that is going to promote a service that best prepares blind children and adults for today's inclusive society. To perhaps better reflect the needs and wishes of the RNZFB membership

and ensure that the needs of the membership are paramount in Governance thinking and actions. David understands that if he is successful and becomes a RNZFB Board member, then once on the RNZFB Board he must abide by the collective decision making process of the Board.

PVI Annual General Meeting 19th November 2011

This year's AGM will be held at the Bella Vista Express Hotel, Auckland Oaks, Auckland Airport on Saturday the 19th November 2011 at 11.30am; followed by lunch. There will be time for parents to mix and mingle and "conversations" ...refer registration form.

Parents are warmly invited to attend and PVI is able to provide reasonable travel costs. As this is a one day AGM there is no need for us to provide accommodation. You have been advised that we are in no financial position to provide a conference weekend as we have done in the past. Hence the one day workshop approach we are providing.

If you are unable to attend please fill in the enclosed proxy form and send to reach us in the office no later than Thursday 17th of November either via fax on 07 839 4535 or mail to PVI AGM Proxy, PO Box 366 Waikato Mail Centre, Hamilton 3240. This is required so that we will meet our constitutional requirement re a quorum.

Positions up for re-election are: - 1 Upper North Island, 1 Central North Island, 1 Lower North Island, a 1 year term for the Upper South Island, 1 Lower South Island 1 Tangata Whenua and 1 Pacific Island. Please feel free to attend and become part of a dynamic governance team.

PVI wishes to **thank BP Vouchers for Volunteers**, PVI has over the past years been very grateful for the support BP offers. This support is appreciated by our volunteers.....



P.V.I. Annual General Meeting 19th November 2011
Bella Vista Express Hotel, 14 Airpark Drive,
Auckland Oaks, Auckland Airport
1 Day AGM Parent Registration Form

Attending Parent-Caregiver/s details:
(Please print)

Parent 1: [Last name] [First name]

Parent 2: [Last name] [First name]

Telephone: Day: Evening: Mobile:

Postal Address:

Email:

Special requests: Diet:
Any Other:

"Conversation" Topics:

We propose to have "Conversations" at the completion of the AGM, please state what you would like to discuss.

- ☐ Early Years
- ☐ Sharing with other Parents—different forms available to communicate now-days
- ☐ Transitions = pre-school, primary, secondary post school
- ☐ Relationships: - school, professionals each other etc...
- ☐ Legal aspects such as turning 18 years, Trusts, Welfare Guardianship,
- ☐ Auckland University Eye Department Gene therapy database; should your child be on it?
- ☐ CRPD = Convention on the Rights of People with Disabilities = making it work for you locally
- ☐ Other; please state

Parent Confirmation of Membership:

I confirm my child:(name of child needed to confirm membership) has a serious sight loss condition and that I am a registered parent/caregiver of Parents of Vision Impaired NZ Inc

Signed:

Registrations requiring Airfares close Friday 21st October 2011
Or Wednesday the 16th of November if you do not require airfares.
Please post this form to Parents of Vision Impaired, PO Box 366, Waikato Mail Centre
Hamilton, 3240 or Fax: 07 839 4535

PVI will pay for reasonable travel, Lunch and refreshments upon arrival. Should you wish to stay on the Friday or the Saturday evening then these costs are on you. These costs include, accommodation, food and any extra difference in airfares. If the travel PVI books for you means you have to stay overnight then these costs will be born by PVI.

RNZFB Board/PVI Sustainability/Vision Magazine

The Board of Directors of The Royal New Zealand Foundation of the Blind has voted to decrease consumer group funding annually until the Board decides other-wise. This is very clearly the message we have received. Such was our concern, PVI initiated a meeting with the RNZFB Board of Directors. We met with a small delegation of the Board at Awhina House Friday, 2nd Sept. The meeting with PVI stating very clearly and with some passion at times, that we, as a consumer group, felt the changes to funding needed a face to face discussion. It is too early to advise of outcomes of this meeting as we are still working through processes of where to next.

With regional RNZFB office closures, and a lack of staff employed in the Children's Services division our voice of concern was heard. There is some strong views that, the RNZFB membership is currently not being listened to. We can assure you that our concerns were heard and listened to. A real disconnect is occurring...

As your Executive Officer, I have never had to speak to RNZFB Board Directors in the manner I did at this meeting; such was my concern. I have never seen or heard from so many parents with calls of concern, with frustration at some decisions being made without consultation with them as members. It appears to many parents that there is no real understanding of how tough it is raising a child that is blind. The membership of PVI is very concerned, in fact PVI has also heard from other adult members who are voicing similar concerns.....what are we to do ?

*"If you always do what you have always done,
You will always get what you have always got!"*

The above quote springs to mind. It is easy to get negative and throw the toys from the cot at times like these..... Let us not fall for this level of behaviour, let us instead look for opportunities, looking for ways to grow PVI perhaps with less financial support from the RNZFB. We must not remain solely reliant on the RNZFB for our funding. This funding is our "Achilles heal" so to speak. This is why we have embarked on other avenues of fundraising they are and are not limited too:

- Support PVI by signing up to Kiwi Tel as your Telecommunication provider. If you do, Kiwitel will give to PVI 5% of the gross amount of the monthly account. There is no cost to yourself, however, please be aware that if you have not completed the term of your current contract, an early termination cost may be charged by your current provider.

Please feel free to ring me to discuss this further. We in the office, have signed over!

- Support PVI by direct "Payroll Giving". If you instigate this, you will receive an immediate 1/3rd tax refund..... Every little counts.
- Think about PVI in your will, legacy giving is important.

"Vision" Magazine:

For many years, "Vision" has been the flagship of how we communicate with and advise our parent community. We believe it is well received, however we cannot continue to produce the magazine in printed format, given the current funding constraints.

We have some tough decisions to make: -

1. Produce "Vision" as a download from our website.
2. Produce "Vision" as a download with PVI advising you via an email link to "Vision" mag. To do this, you need to provide PVI with email details to keep receiving "Vision".
3. Produce "Vision" in a printed format with a reduced mailout i.e.: - printed version mailed out say quarterly. This is a 30% reduction in printing and postage costs.

The preferred option at this stage is option 2.

We purposely have not looked at charging a cost to receive "Vision". This could prove more costly to administer than it is worth. The above are the preferred options.

Please advise PVI how you wish to receive "Vision" by contact the office on 0800 312 019 or email paul@pvi.org.nz or lyn@pvi.org.nz

Paul.

Children's Spectacle Subsidy update

The Health Committee recommends that the House takes note of this report.

Spectacles subsidy:

The Ministry of Health subsidises the costs of vision testing and glasses or eye patches for children who need them. Whilst it has overspent its funding for the subsidy, the ministry is using money from other parts of its disability budget to continue providing the subsidy and have agreed, for the time being, not to change the criteria for the subsidy.

Consumer advocacy at work!!!!!!



Gwen Nagel's dream realised –A new Homai School

Monday 29th August 2011, the new Homai Campus School of BLENNZ was officially blessed and as such is open for business. Think about this, our new school for our children \$14.9 million. A leading design, we are advised it is cutting edge technology and a world class facility.

This journey of a new school had its beginnings back in the mid to late 80s. Gwen gathered her troops consisting of PVI and RNZFB staff and governors' and of course Homai staff. We all dared to dream, to dream of a national school that would serve as a hub for the other Vision Resource Centres around the country..... We had to convince the Ministry of Education and in time we did.

Gwen was not alone, I recall parents from those days talking with much passion as to what they envisaged. I think of parent leaders of the time re Georgia Kenyon, David Heather, Cloan Magill, and of course Raewyn Edwards. Of how we had to learn to work with each other, learn to trust each other and of course learn how to get the government on board. Fast forward to May 2008 and PVI initiates and present a petition to parliament. One of the outcomes of this petition was a complete new school rebuild of Homai school. By 2008 PVI and its sector friends had learned how to best advocate, our petition along with other factors ensured our voices were heard.....

First impressions of the new school are WOW, it is so light and airy. Upon entering the building one is taken by the wonderful colour contrast themes. You get excited by the colours, kids will just love them, the tactile handrails and flooring also have excitement factor too. It is all open plan with the exception of some storage and smaller rooms. Inside I could not hear an airplane overhead or a train passing by! Double glazing glass throughout, lots of glass..... The Ministry of Education have advised the school has an environmental rating of 5 stars which means it will be cheap to run

The accommodation wing is a wee walk adjacent to the school where the old early childhood centre was. A modern little kitchen, rooms that are interchangeable, modern clean toilet areas with showers designed for adults as well as children YES!

Supporting PVI on the day were Rahui and Kiriana Tata Kaumatua and Kuia, Whia Kitty Tuari, Don Fairgray from the BLENNZ/PVI Board, and David Heather as our elder PVI statesmen. Kitty reports all went well with Ngati Kapo doing a stirring job. Local Kaumatua Eru Thompson, Rangi McLean and Bob Clark blessed the building and all areas inside.



Part of the crowd assembled for the blessing ceremony, seen her entering our new school.

Architect John Sofo reports: - The new BLENNZ facility is probably a world—leading example. There are areas where the building are unique and innovative not only by New Zealand but international standards. There are a variety of acoustic experiences within the building so those skills can be developed.

Throughout the years one person has been rock solid I her support for the new BLENNZ concept, she was at Gwens right hand throughout the years, to Jane Wells current CEO/Principal of BLENNZ we say thankyou.... To our friends in the Ministry of Ed we say thankyou. To our children we say make the most of this wonderful learning facility grow and learn.....

Thoughts from parents present at the 'Blessing'

"The Blessing. BRILLIANT, MOVING and inspirational. Loved and humbled to be part of it. There were probably 150+ people there."

"Attended the blessing early Monday morning at Homai. It was a great morning and topped off a long wait to see many of our dreams starting to take place. I guess I have seen the good , the very good , the bad and the ugly in terms of school administration and watched parents, families and all associated wanting participation and partnership. Back in 1971 the institution mentality prevailed and the only committee that existed was the Admissions and Discharges Committee and not a parent allowed near any governance issues. WOW how time changes things. The blessings were very sincere and moving indeed."



Housing NZ, Shame upon you.....What took you so long?

Friday 5th August: -

PVI prints this with permission from a strong PVI parent advocate, one who is utterly frustrated by the inaction of Housing NZ staff in Christchurch. The following is her story....

We lost our fireplace in our Housing New Zealand rental property in the February Earthquake. I have constantly rung them with the help of support services, required the medical certificates to prove we are in need of heating everything I can think of but to no avail. We have had many promises of the job being done, the workman came in to measure and order the new fireplace in June, the inspectors came a number of times.

We are constantly cold in our home. We live in the lounge where we use three heaters to keep warm. My son eats, shaves and brushes his teeth in the lounge. He has not been in the kitchen for months and dreads having a shower.

To enable him to shower we have to use 7 heaters: to warm his clothes, to heat the shower room, hallway and his bedroom where he gets dressed. What we used to pay fortnightly for power has now become weekly.

Most times Tyler is fully dressed with slippers inside a sleeping bag. It is very difficult when he is unwell as he becomes incontinent which restricts his limited movements as well. Pyjamas are a thing of the past, we are fully dressed when we sleep. He has missed a lot of school and cried because he is so cold. We are constantly sick especially in mid-winter and so medical bills are sky rocketing.

Am I worn out with the above YES? Is it my job to spend my precious time to chase the service providers up for everything and to prove we need something? NO it is not my job.

It is now August and the weather forecast is for more snow. Tyler is off school yet again sick with flu. We just paid a personal visit to HNZ and heard another string of excuses, the quake, snow, the workmen, people with sewage in their homes and they did loan us a heater which can only be plugged into certain rooms because the fuse blows.

Our fireplace issue is not just because of the quake it has been an issue for the past two years when I relayed a letter from the Christchurch City Council stating our fireplace was too old and needed to be replaced.

According to the Christchurch City Council the building permit for the fireplace has been **approved in June 2010.**

I personally do not know why we, the vulnerable, are being treated the way we are.

This is our daily living. We're freezing, sick, tired, frustrated and awfully down about our circumstances.

No I do not want the community to feel sorry for us and help us out. What I want is Housing New Zealand to honour their contract that they provide the appropriate services to the tenants.

Andrea.

On Tuesday 9th August: A New Log-burner installed, Andrea and whanau now live in a warm home!

PVI did make an enquiry to **Minister Hide** on Friday, 5th August..... He is not taking any credit. However, it does appear **very coincidental** that **PVI seeks help on Friday and by Tuesday the matter is sorted.** You be the judge....

Sad that this action had to be taken, to get as Andrea puts it, "What I want is for Housing New Zealand to honour their contract that they provide the appropriate services to the tenants".



**Kiwitel cares, do you?
Sign up & support PVI**



VISION 2020 NZ and the CLEAR FOCUS campaign....

Hello All,

Please find below the update on the activities of Vision 2020 NZ activities and how you can be involved.

VISION 2020 New Zealand's Clear Focus

VISION 2020 New Zealand's Clear Focus research was launched at Parliament on 2 August, at an evening event hosted by National MP Dr Paul Hutchison, Chair of the Health Committee. Thank you to those of you who were able to attend the event - it was great to see you there.

Other attendees at the launch event included MPs from across the House, Ministerial officials, representatives from District Health Boards, eye health professionals and academics, sight loss related disability organisations and colleagues from the disability sector and blind community. The event's MC was Darren Ward (cbm New Zealand) and speakers were Dr Paul Hutchison (National), Grant Robertson (Labour), Kevin Hague (Green Party), Don McKenzie (as chair of VISION 2020 New Zealand) and Sandra Budd.

The event also launched the Clear Focus campaign, which is advocating for a comprehensive national eye health strategy to eliminate avoidable blindness in NZ and ensure better services and inclusion for people with vision loss. The campaign has so far been endorsed by the RNZFB, cbm New Zealand, Macular Degeneration New Zealand, Glaucoma NZ and Vision 2020 Australia.

We would like to invite your organisation to consider endorsing our Clear Focus consensus statement to show your support for a comprehensive national eye health strategy. It will be hugely important to ensure that consumer interests and perspectives are included in the development of the strategy.

Official support for the campaign would mean that VISION 2020 New Zealand would use your organisation's name and logo on their website and publications in reference to the consensus statement, and would mention your support at meetings with political and sector contacts. They would keep you up to date with campaign activities and provide briefings on opportunities to become involved.

As an individual, you can also sign our [online support statement](#) to personally endorse our campaign. Online signatures collected at the launch event include MPs Grant Robertson (Labour), Colin King (National), Kevin Hague and David Clendon (Green Party).

You can access the online support statement at: <http://www.thepetitionsite.com/1/clear-focus/>

The full Clear Focus report and an overview of the research are available to download from VISION 2020 New Zealand's website in PDF and accessible Word formats. The web address is http://www.vision2020.net.nz/clear_focus

You can also follow VISION 2020 New Zealand on [Facebook](#) and [Twitter](#) for updates on the campaign and our progress, at <http://www.facebook.com/VISION2020NZ> and <http://twitter.com/VISION2020NZ>

Please feel free to share these links with your colleagues, friends and family.

Regards

Sara Peary, Executive Director Stakeholder Relations
Royal New Zealand Foundation of the Blind
Awhina House, 4 Maunsell Road, Parnell, Auckland 1031
Mobile: 027 234 6863, Fax: + 64 9 366 0099

PVI Response: -

For too long this country has provided eye health services in an ad hoc manner. With the advent of Vision 2020, we have an opportunity to have a national policy around eye health care...naturally PVI is most willing to support any improvements around the eye health care of young New Zealanders in particular. We will have to be a squeaky hinge as I fear it might become adult focused!

RNZFB Blind Week

Would you like your pre-school aged child to be part of the Blind Week and perhaps a front person on TV, then please contact Paul on 0800 312 019 or email me at paul@pvi.org.nz for further information or Collette Pellett, Marketing Executive, Royal New Zealand Foundation of the Blind DDI 09 355 6885

Pacific Vision Equipment Sponsorship

The Pacific Vision Equipment giveaway application date has closed. (Friday, 16/9/2011).

The selection panel will be meeting over the next two weeks to decide the winners, who will be notified directly, and we shall publish the results in our next issue of "Vision" as well as the RNZFB "Outlook" magazine.

LOVE, DATING, AND MARRIAGE: BLIND CHILDREN GROW UP AND BECOME PARENTS, TOO by Barbara Pierce

(This article is taken from remarks made by Barbara Pierce on June 27, 1987, at a seminar for parents of blind children at the convention of the National Federation of the Blind in Phoenix, Arizona. Mrs. Pierce is the Assistant Director of the Alumni Association of Oberlin College and is President of the National Federation of the Blind of Ohio.)

I truly believe that the only people who maintain that they would gladly relive those vital, exciting, youthful years of their teens over again are the ones who can't remember the details. I see that all of you had adolescences just like mine—agonizing. I have great news for those of you who are parents of younger kids. I tell you as the parent of (count them) three teenagers, that parenthood of teenagers is just like being a teenager all over again, with all of the pain and agony except that you're doing it vicariously; and, therefore, you can't do anything overt to be helpful at the time. All you can do is sit and suffer.

I will go on to say that every kid that ever lived through those teenage years had the conception that he or she was an ugly, clumsy misfit, who never knew the right thing to do and was never going to be picked to be married to anybody and would always be counted on to fall over his or her feet. At least, sometimes that's the way every kid feels about himself or herself.

Blind kids are no different from any others in feeling that way. The manifestation of those anxieties and fears may be somewhat different sometimes. But the underlying feeling of inadequacy and uncertainty is, I think, the same for all adolescents. And I think it's particularly important that parents of blind children hang on to that sense—that fundamentally you have in your background the experience (the reservoir) of those same kinds of feelings. It's not helpful ever as a parent to say, "I know just how you're feeling." Because every kid is reinventing the wheel and is the first one ever to agonize. But, at least, remember that even when you feel most at sea about whether or not you have anything really to communicate with your youngster about because of the peculiar circumstances of the situation, you've got the emotional underpinnings of it.

I would say that from the early stages (but it is particularly necessary when you are dealing with teenagers) it is critically important that you make sure that they have good role models.

You must see to it that blind teenagers meet and get to know and establish friendships

with competent, articulate, successful blind adults. It's important that blind kids know that it's possible to grow up to be a really normal human being who does know which fork to use at dinner, who does remember to put his napkin in his lap, who does know what to do in an awkward social situation. It does happen. A lot of us as kids were really bereft of that sort of experience. I truly grew up throughout the early part of my teenage years really having a conviction deep down inside of me that I would never marry. Who would want to marry a blind girl? I was the only blind person I had ever known. I had seen a few blind people selling pencils on streets and playing the accordion in various places in Pittsburgh, and I was quite certain that if one grew up to be like that, I knew nobody would want to marry a blind girl. I wasn't sure that I ever would grow up to be the kind of person that some other human being would elect to spend a life with. So that's why I think role models are terribly important.

The next thing that I would say is that you need to start early. Again, I go back to what one of the previous speakers said. It's hard sometimes to take the time to make the kid pour his or her own bowl of cereal, but you've got to start early teaching a youngster responsibility. How are you ever going to have a teenager who is going to care about the state of his clothing and remember to wash her hair every night or every other night or remember to pick up things and be neat about their lives so that they're acceptable to other people if you haven't started early training that youngster to tie shoes neatly, to tie a tie, and to do all the things that go into civilizing the young of the species? You just have to start early.

You also need to teach social skills. I may be getting into deep water here, but I think social skills are terribly important. It is not an easy thing to do, and in part it is not an easy thing to do because you are dealing with a teenage culture which is different from an adult culture. You don't want to turn your kid into a little Lord Fauntleroy at the age of ten, always wearing a perfect little suit. But it is important, for example, that blind youngsters who do not have any vision at all be trained in the importance of looking at the people they are talking to.

Have you signed up yet?



LOVE, DATING, AND MARRIAGE: BLIND CHILDREN GROW UP AND BECOME PARENTS, TOO

by Barbara Pierce (cont.)

It is disconcerting to anyone to have a blind person stand and talk to him or her three-quarters turned away—especially if that person happens to be sighted. It is terribly important that you teach those things. Nobody's going to want to go out on a date with somebody who's not paying any attention to them. You communicate to a sighted person that you're paying attention to them by looking at them, for heaven sakes.

You teach a blind kid the importance of standing up straight and holding the head up straight. Again, with some kids it is a harder struggle than with others. I don't know whether it would have been a hard struggle for my parents. They managed to do it in a way that I think was positively ingenious. I am not a small woman. I'm five seven and a half, but I'm the shortest one in my family. From the time I was a kid, any time my father measured us to see how tall we were, he went through this song and dance of, "Well, you're getting there. You're not there yet. But if you stand up straight, you'll be a little closer to being there." My mother's five eight. He said, "The only problem with your mother is she's not tall enough."

I've never asked them whether, in fact, they ever did this consciously, but several times in my childhood I have a vivid memory of running along in front of my parents and hearing my mother just sort of comment to my father, "Look how straight she stands. When I was a kid, I was so self-conscious about my height that I slumped, but she stands beautifully." Now, that was not directed to me. It was pointedly directed at someone else, but little pitchers have big ears. I heard and understood and was motivated to stand straighter—to keep my head up, to look up.

Another thing that I think is terribly important for children to learn is to eat with good table manners. I will never forget one of my brief sorties into a residential school for the blind. I was to be tested as a junior in high school. They couldn't find an IQ test that I didn't top out of, so they were doing some special oral test that could only be given by the psychologist at the school for the blind. He tested me all morning long. Then, he said, "I've got to go teach a class, and I wonder whether you'd be willing to come in (these are seventh and eighth graders) and talk to them since you are in a public high school, and some of these kids will be going to public high school. Just talk to them about what it's like to be in a public high school."

So, I went in and talked to them. And just in passing:

I had a friend who had moved to a different school district, and there was a blind girl in the school district; and Betsy had told me that the kids would grab this child up and haul her through the cafeteria line, and then they'd plop her down at a table and go off somewhere else. This poor kid sat at a table all by herself in a crowded lunchroom because her table manners were so appalling that no one of those kids (and you know what kids' table manners are like) wanted to sit and watch her eat her lunch. Now, those were appalling table manners. Having that in my background, I simply happened to mention to these kids how important it was not to hunker down over your lunch and sort of shovel it in as though you were in mainland China with your bowl of rice and your chopsticks (where that's the approved manner of eating) but that it was important to use your fork and knife correctly and to put your napkin in your lap and to remember to use it—not to eat coleslaw with your fingers, and all these little details of life that do alienate other people when they have to sit and watch it. Anybody who has lived through getting a toddler to eat is pretty hardened to bizarre table manners. Some of us don't ever raise the standard again with a blind child. I think it's really important that that standard be raised.

It's important that a kid be taught the elements of neatness. You can't live the kid's life and go running around tucking the shirt tail in at the age of twenty-three, but at least it's important to give the kind of feedback that says: A neat appearance is important. A clean appearance is important. We must check your clothing at the end of the day to see if it's got spots that need to be treated. If you don't see well enough to observe those things yourself, it's going to be important that you line up somebody who will look for spots and help treat them with spot cleaner. It's important that clothing be clean. It's important that you be clean. It's important that, after a certain age, you use deodorant. It's important that a teenager learn that hair must not be washed just once a week but, depending on how oily the hair is and how exuberant those oil glands are, the hair be washed frequently**. Styling is going to be important. Girls have got to learn about appropriate application of makeup. Both sexes have to learn what colours look best on them. These are things that are important for a kid to learn and for a parent to take responsibility for seeing that the kid learns—whether or not they are done by the parent or by someone else.

LOVE, DATING, AND MARRIAGE: BLIND CHILDREN GROW UP AND BECOME PARENTS, TOO by Barbara Pierce (cont.)

I guess the other thing I'd say is that it's important to try to teach a child to be genuinely interested in other people. People who are totally preoccupied with themselves and their difficulties are not very pleasant to be around. It's easy for blind kids to trip out on this because everybody's always wandering up to them and telling them (just because they have mastered tying their shoes) that they're just wonderful and inspiring and all of that. Kids can get very caught up in, "Everybody's interested in me." Everybody may pretend to be, but not everybody is—and certainly not all of the time. It's important that kids learn to be interested in other people and learn the conversational gambits of asking good questions to elicit information about other people.

Today's dating patterns, I think, do make it easier for blind kids to date. When I was a teenager, the girls sat around chewing their fingernails hoping that somebody would ask them out, and the boys sat around chewing their fingernails wondering if they were going to get kicked in the teeth if they asked a girl out. It was generally a sort of mystifying and pretty uncomfortable situation, because there was always pairing off or pairing off in multiples of two. Now it's different. My own daughters go out in a gang, and some people will start out together and others will end together. Some of them are just sort of there as part of the group. That sort of group activity is, I think, extremely helpful to a blind kid. Encourage your youngster to participate in that kind of activity. I'm going to give you the "Pierce Plan" for socialization. This is the one that I developed as a kid, because I rapidly learned that the girl who had no experience got no experience. It's that catch twenty-two of getting a job. We want to hire people who have had jobs, but how do you get hired for a job unless you've had a job? You've got the same sort of thing for a youngster. So you get the experience in a group, and then you start dropping references. "We saw this neat movie last night." So maybe it registers in the mind of someone that, "Gee, that kid might be blind but I guess goes to movies—must be all right to go to a movie." Or, "You know, there was this terrific wrestling match we had out on the lawn, and I got covered with grass stains." Teach kids to drop hints to let other people know that they're human—that they do these things like everybody else does, that they have fun, that they don't break, that they participate wholly in activities. You need to be the person to encourage that kind of dropping of references.

Basically I would say that the more comfortable the kid is with being blind, the more

comfortable everybody around him or her is going to be. Whether or not the kid is comfortable with blindness in the first instance comes back to whether you are. At least, the younger they are, the more that is likely to be true. That's why it's really good that you're here—that you're here among blind people, that you're here openly talking about blindness. I have the two most terrific parents in the world, but my mother (when I was a kid) would have died rather than openly to confess to anybody that she had a blind child. So I always knew that it was important that we pretend that I wasn't blind, which was a little tricky as I began using a white cane and Braille. I had to hide the stylus. I had this nifty place behind the sofa where I scooted the cane as soon as I came in the front door so that she didn't have to see it.

Even if a kid isn't fully comfortable, the kid is always capable of pretending that he or she has things under control. There was my physics class in high school. We had physics groups, and they put me in a group that had my brother in it, for one thing. (I'm sure that the teacher thought that he could take care of me, but I was the senior. He was the junior, so I had to keep him in line.) But this real hunk of a guy was in this group as well, and I didn't know how I could pull my weight. I couldn't read the slide rules. I decided to take as my turf knowing what was supposed to be happening. I laid it out to these people:

"Look," I said, "I can't do a bunch of this kind of stuff that needs to be done, because it's real close work, and I just can't see it. But I will undertake to have studied the experiment the night before in the lab manual and know enough about what's going on in the textbook so that I can keep us straight on what we're supposed to be getting—not that we're going to cook the numbers, but at least we keep trying until we have them right." I came to terms with what I could do, and I went and did it. That guy turned out to be my passport into the world of dating.



LOVE, DATING, AND MARRIAGE: BLIND CHILDREN GROW UP AND BECOME PARENTS, TOO by Barbara Pierce (cont.)

Let me talk about whether a blind person should date another blind person or someone who is sighted. I think there are good and bad reasons for doing either one. And there are advantages and disadvantages to doing either. The advantage to dating somebody that's sighted is that the world is mostly made up of sighted people. Therefore, you have a larger pool of people to draw from. At least, theoretically, it ought to be easier to date a sighted person. The wrong reason for dating a sighted person is because that person can take care of you or will keep you safe. I have to tell you that that's the most appealing reason for most parents—especially of daughters, because what they really want is somebody that's going to make sure that nothing happens to their little girl—and can a blind guy keep her safe? There are all sorts of pitfalls to avoid—whether your male companion is sighted or blind. So you just sort of take your chances. I would say that the disadvantage in a blind person's dating another blind person is being sort of stereotyped. You (and others) may think you're not good enough to do anything else. Of course, that's predicated on the notion that blind people are inferior. That is a bad reason for dating a blind person—the concept that one is lowering one's sights to a narrow group of people. Incidentally, it is a bad idea to limit yourself arbitrarily to any narrow group. It would, for instance, be dumb to date only redheads. But there is this sort of general feeling that—as one of the previous speakers put it— you can relate to other blind people. To which I say, "Well, bully." I want the next generation of blind kids to grow up so emotionally healthy and tough-minded that there simply won't be any question of whether anybody needs to relate to somebody else personally because he or she is blind. The good reason for dating a blind person (and candidly the reason that I wish I had dated some blind people, except I didn't know any until I had already been married and had three children) is that it really does engender a kind of independence. You can't be taken care of, and just sort of cling to the arm of your date for the evening if both of you are blind. You had both bloody well better be caning. You can hang on, but cane, too. It does foster independence. And I think that is a really good thing for a blind kid to experience. I would say that a blind person should always cane on a date with a sighted person, and I mean more than just taking your cane along. I mean use it. Don't fold it up and put it away. Use it. I would say it takes maturity for a sighted person to date a blind person and to feel comfortable with that person.

I would warn you parents that there are an awful lot of sighted people out there who are looking either for a mother or for somebody to take care of them—or who are looking for somebody to mother. Such persons tend to home in on blind people. And you just have to depend on raising your kids so healthily that they will pass through that period and not get stuck in a marriage with that sort of relationship.

I guess in closing I would say that blind kids need a lot of feedback. They need honest feedback—what they did well, and (positively and gently said) what they didn't do so well, or what they need to have done. Be prepared to give that feedback or to nurture relationships for your youngster where there are people who can give that kind of feedback to your kid. It's terribly important. Those fragile egos do need to be buoyed up, so it needs to be done positively. If you tell a kid, "You must remember to wash your hair tonight—it really is getting kind of dirty," then the next morning remember to tell the kid how good it looks now that it's clean. That sort of thing needs desperately to be done.

I will simply say that once you get into a relationship where somebody does think that you are a pretty terrific person, it changes the way you feel about yourself. That's what I want you to remember. Nurture that and expect that for your children.

Delivered as a speech in 1987 by a blind woman, mother, advocate and a passionate human being..... Still very relevant today.....

Hi

I just came across a webpage that has a list of listserve/forums that people can join: adults who are blind, families with blind kids, high school blind kids

New Zealand is a small country and it does make sense to use the Internet and forums as much as possible to ask 'those questions' to people who are experiencing the same sorts of issues wherever they live. And make new friends through the Net too.

Paul, you might want to add it to your newsletter and/or website too.

<http://www.jwen.com/rp/listblind.html>

Just thought I'd share.

Kind regards,

Natalie Perzylo

Developmental O&M/ADL Instructor RNZFB

Bikes for Kids 2011



Variety – The Children's Charity is currently calling for nominations of deserving children to be recipients of bikes on its 2011 Bikes for Kids tour.

This year the Variety Bikes for Kids tour will be travelling from South Auckland through Cambridge, Taupo, Ruapehu District (National Park, Ohakune, Raetihi),

South Taranaki, Porirua, Lower Hutt, Wairarapa (Carterton, Featherston), Hastings and Napier from 13 to 18 November. The tour will also start with an additional presentation to children in Christchurch on Friday, 11 November.

To receive a bike a child needs to be:

- Aged between 7 and 9 years (between 111 cm and 135 cm tall)
- A role model to other children OR
- A child who has consistently made a difference within their school and community environments and has shown an outstanding ability to assist those around them OR
- Socio-economically disadvantaged, with their family not in a position to purchase a bike OR
- Have recently overcome some adverse circumstances.

If you know of any children who fit these criteria and deserve a bike, please fill in the attached nomination form, download a form from www.variety.org.nz or call 09 520 4111. Completed forms can be emailed to helpkids@variety.org.nz, faxed to 09 520 1122 or posted to Variety – The Children's Charity, PO Box 17276, Greenlane, 1546. Nominations must be received by Variety by 7 October 2011.

Bikes for Kids 2011

Each year Variety – The Children's Charity supports more than 10,000 Kiwi kids, their families and communities. Since 1989 Variety has given more than \$12 million to help sick, disabled and disadvantaged children.

The annual Variety Bikes for Kids Tour is part of the Variety Kids on the Move mobility programme, which provides life-enriching assistance to Kiwi kids.

Each year Variety provides around 450 deserving or disadvantaged children with the freedom and independence of their very own bike.



2011 Bikes for Kids programme

This year the Variety Bikes for Kids tour will be travelling from South Auckland, Cambridge, Taupo, Ruapehu District, South Taranaki, Porirua, Lower Hutt, Wairarapa, Hastings and Napier from

13 to 18 November. We will also start the tour with an additional presentation to earthquake-affected Christchurch on Friday, 11 November.

The Bikes for Kids tour travels in a Variety Bikes for Kids-branded truck. Presentations take place at parks, schools and sponsor premises. Variety Ambassadors and celebrities MC the presentations and assist in handing out bikes to the children.

Schools and communities in each area are invited to participate by nominating a deserving child to receive a bike.

Nominate a Child

If you know a child in one of the areas noted above you can nominate them to receive a brand new bike of their own. The nomination form is on the next page *.

To receive a bike a child needs to be:

- ☐ Aged between 7 and 9 years (between 111 cm and 135 cm tall)
- ☐ A role model to other children OR
- ☐ A child who has consistently made a difference within their school and community environments and has shown an outstanding ability to assist those around them OR
- ☐ Socio-economically disadvantaged, with their family not in a position to purchase a bike OR
- ☐ Have recently overcome some adverse circumstances.

Please note the child must be able to attend the presentation in their region to receive their bike.

The times and locations of the presentations are yet to be confirmed, these details will be on the Variety website when available. Please refer to www.variety.org.nz for updates.

The recipients will be selected from the nominations received. Each application will be considered on its merits. Allocation of bikes is at the discretion of Variety - The Children's Charity. All applicants will be notified of the decision by 29 October 2011.

Variety – The Children's Charity.

PO Box 17276, Greenlane, Auckland 1546.

Email: jodi@variety.org.nz



The Review of Special Education

"Success for All – Every School, Every Child"

Aggregating Sensory Resources

Key messages from 24 August 2011

Staff from the three sensory schools updated their reports on visits to enrolling schools and finalising of service arrangements for 2012. The sensory schools are now considering options for more staff in 2012. Some enrolling schools will have staffing transferred back to them and arrangements for that will be finalised by the end of term 3.

The Principals from the team continue to meet with stakeholder representatives and parent groups to update them on progress with the Aggregation of Sensory Resources Project.

Study Award applications close at the end of September and registered teachers with an interest in the education of students who are Deaf and hearing impaired, or Blind and low vision are being encouraged to apply.

Another letter from the Ministry, will go to all schools with ORRS sensory students who will have their staffing aggregated, updating them on progress and plans for 2012. The letter will go at the same time as the 2012 Staffing and Funding Entitlement Notices in early September. The Circular that goes with the Staffing and Funding Notices will note that there will be changes in 2012 to the staffing entitlement. The details of the changes will be sent to individual schools in December. Enrolling school's staffing notices in December will show the ORRS sensory student by name and the sensory school the staffing will be provided to.

Separate letters will go to private schools explaining the changes that are going to happen for state schools. As private schools do not get staffing entitlement there will be no change for them in 2012. Private schools receive the ORRS 0.1 or 0.2 as a cash grant and changes to this and other cash resources i.e. teacher aide funding, will be considered in 2012.

Special Schools will be informed that the Deaf Education Centres (DECs) will transfer staffing for any students enrolled in special schools.

Senior staff from the DECs and BLENNZ will connect with Ministry of Education, Special Education service managers over the next month to ensure local arrangements are in place to manage any concerns as we go into the transition for aggregation in 2012.

The next project management team meeting is scheduled for 4 October 2011.

Background to Aggregating Sensory Resources

This policy initiative is the result of:

- feedback to the Review of Special Education discussion document. The majority of the feedback came from parents. Educational staff, advocacy and interest groups also contributed.
- the need to get a more flexible and responsive service which meets the individual needs of children with sensory impairments the Ministry of Education working with the sensory schools over time. In particular, this initiative follows on from the work of sensory schools to match student need with specialist teacher capacity.

Benefits of policy initiative for children

- allows for more flexibility in how and what resources are provided
 - allows for redefinition of types of workforces to most appropriately meet student need
 - will strengthen relationships between sensory schools and regular schools which have children with a sensory impairment on their rolls will allow for more direct access to specialist teachers
 - supports specialist teachers to manage workloads efficiently to meet the needs of individual students
 - allows opportunity to strengthen and build professional development of those working around children with sensory impairments
 - contributes to lifting confidence of schools through providing better training and understanding
 - will increase access to a wider range of services by families
- strengthen collaborative approach of the team to supporting the learning needs of individual children.

Contacts

Yvonne Hope Project Manager Ministry of Education
yvonne.hope@minedu.govt.nz

Bernie Mulcahy, Principal, van Asch Deaf Education Centre
bmulcahy@vanasch.school.nz

Jane Wells, Principal, BLENNZ
jane.wells@blennz.school.nz

David Foster, Principal, Kelston Deaf Education Centre
davidf@kdec.school.nz

"This and That"

Cold but beautiful in Oamaru

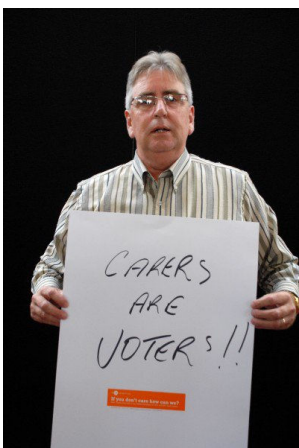


25th July 2011

Hi there. Yes, we are hunkered down in a burrow here. It began snowing about lunchtime yesterday, on and off, but around 5pm it really snowed heavily, and carried on thru most of the night. By then the roads were soaking wet, and they subsequently froze into black ice underneath the snow. It has made moving outside a very treacherous business. Our paths are all lethal, and getting the dogs outside for a pee was a bit of a mission. We ended up putting some old carpet on the steps and paths so they didn't break their necks. The chihuahua was absolutely terrified of the snow, stood there on tiptoe with the snow almost up to his "man bits" (or where they used to be until he was neutered,) shaking. We picked him up threw him under a shrub, he peed, then we tossed him back in thru the catflap. The miniature poodle went out, lifted his leg, then shot back inside. But the standard poodle turned into a right fruit-loop. She raced back and forth along the back lawn at 90 miles an hour doing slides and skids, she gobbled up falling snowflakes, licked snow, chased snowballs, and generally lost the plot completely. Once dragged back inside, she curled up in front of the fire as if to say "glad that's over."

This afternoon it is all starting to melt, and all the pretty is gone. The temperature outside has gone up from -2 to a far more comfortable 4 degrees. There is a large pile of wet coats, gloves, and shoes to sort out in the laundry.

I had always planned that a large snowfall would occur during a school day, and the kids would be trapped at school, (and Steve at work,) while I was here all alone with a pile of firewood, a decent bottle of wine, some nice snacks and a good book. It had a certain appeal. I hadn't anticipated them all being here with me!!!!!! Blew that theory!! Pat



Carers Alliance of New Zealand has started a **'We Care' campaign**. This campaign is about the need for a more fair system around the needs of the unpaid carer like us as parents of our disabled children. www.wecare.org.nz On this website you can email the Prime Minister direct or send a post card of concern.

Left is Paul Manning E O of Parents of Vision Impaired advising carers of their power when voting at this year's general election..... This was taken at the official launch of the "We Care" campaign...

At no financial cost to you



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: Anidria Foundation International.

www.aniridia.org: Anidria 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 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: 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 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

Assoc Min of Education—Sp Ed:

rhide@ministers.govt.nz

PVI Regional Support Vacancies:

We need more parents to volunteer as Regional Representatives in the following areas: - Northland, Auckland, Waikato, Taranaki, Palmerston North, Dunedin and 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 the time to give and wish to further support us please contact **Paul: 0800 312 019**

Make the change and support PVI



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

Dargaville: Gaynor Edgar 09 439 4439

Wellsford: Kim Lewin 09 422 1012

North Harbour: Linda Moore Carter 09 442 1330

Auck. Central: Vacancy please apply

Auck. South: Kawaljeet Singh 09 299 8028

Auck. West: Paulette & Rodney Francis 09 835 1232

Auck. East: Kawaljeet Singh 09 299 8028

Tirzah Shepherd 09 530 9539

Hamilton: Maxine Jeffery 07 853 7006

Tauranga: Linda & Don Fairgray 027 286 7798

Rotorua: Lex & Helen Craig 07 349 3191

Wairoa: Riripeti Paine 06 838 3949

Napier: Lou Halbert 06 845 4706

Taranaki: Vacancy please Apply

Wanganui: Amanda & Rex Van Elswijk 06 345 0327

Manawatu: Vacancy please apply

Wellington: Christine Pask 04 527 7585

Kapiti David & Rhonda Heather 04 203 6539

Nelson: Adrian Secker 027 201 1028

Trudy Perrett 03 544 6641

Christchurch: Andrea Lamont 03 980 1566

Oamaru: Pat Fox 03 434 3499

Alexandra Sarah Hinton 03 449 2414

Invercargill: Kim Hartley 03 217 1906