



PVINZ

eVISION NEWSLETTER

Welcome
to eVision
Newsletter #104

Parents of Vision
Impaired New Zealand Inc
Supported by the Blind Foundation



PVI.ORG.NZ



FACEBOOK.COM/PVINZ

We also have a private group for the parents.

EAH GD JOWTPYN



PVINZ BOARD BIO

MATTHEW HUNT

Lower Hutt

"I was born in Monmouth in the UK and have been living in New Zealand since 2003.

I am a father of two children. The youngest, born in 2013, has opened my eyes to the world of vision impairment and continues to show me that challenges are there to be overcome, worked around, ignored or endured. We appeared together on the front cover of the Ministry of Education's Vision Book and I'm proud to be supporting him on his journey.

I'm a serial volunteer and a computer expert. I've been programming computers since I was eight years old and somehow haven't managed to kick the habit. I work as an IT project manager, but enjoy lending my talent to organisations when I feel that I can be helpful.

I volunteered for the Lower North Island board position at the 2016 AGM in the hope of giving something back to PVINZ who, along with the Blind Foundation and BLENNZ, have given us support and guidance since we entered their communities."

STACEY DODD

Hello!

My name is Stacey. My husband, Joe and our son, Thomas, currently live in Wellsford. Joe and I are owner/operators of the local Four Square and I also make myself available for relieving in the area. I am a trained primary teacher and I am very passionate about inclusive education for all.

Thomas is four-and-a-half years old. He was born prematurely and suffered a brain bleed not long after birth. He has a variety of conditions, one of those being, CVI (Cerebral Visual Impairment). His CVI has improved gradually over the years.

The big focus for Thomas this year will be transitioning from kindy into the local school with an early intervention teacher through the Ministry of Education as part of that transition. Being in a smaller town raising Thomas does come with some challenges with regards to access to therapies and schools however the support of the community has been a positive for us.

As well as transitioning into school, communication has been a large focus this year with having TalkLink come on board to support. I am excited by all the technological opportunities available to our children. I think it is so important to have networks, whether they are in person or via social media. It is a fantastic way to explore, learn, and support one another.



BE A FUTURE BOARD MEMBER

Some thoughts about our annual meeting and participating as a future board member.

We will be staging our annual general meeting at our conference in Wellington on 27 October 2018. Now is the time to start thinking about your organisation and your part in its future. PVINZ had small beginnings to where we are today, and we have over the years kept to the same formulae. We are there as the network for parents and families, connecting, supporting and advocating where needed. More importantly we have fun achieving these simple objectives. We have been extremely well served over the years by parent board members.

If you would like to stand for election as a board member here are a few comments about what is required.

- Board members usually serve a two-year term representing various regions of New Zealand and Tangata whenua.
- The board or national executive committee usually meets three times per year, mainly in Auckland and Wellington, as well as at conference AGM.
- PVINZ pays for all air fares, transport, accommodation and meals to attend.

- The board usually assembles on the Friday evening and disperse on the Sunday morning.
- The board operates with a number of smaller sub-committees so that the workload is spread and is interesting.
- The board operate its own Facebook page, and maintains and oversees the PVINZ Closed Parents Facebook page and the open website and open Facebook.

This year at the annual meeting we will be voting for board members for the following areas:

- Upper North Island
- Central North Island
- Lower North Island
- Upper South Island
- Anywhere in New Zealand
- Tangata Whenua

Over the years we have established a reputation as a respected and high-profile parent advocacy group. As a result we have seen our advocacy result in changes and better resources for all our parents and whanau.

If you are interested please contact 04 293 8236 or 0274 402 073 or email david@pvi.org.nz

E VISION 104

HOW LONG IS TOO LONG?



Picture this scenario circa 2014. Being parents of a special needs child aged four, about to embark on the education journey. After a four-year period of pushing through the grief barrier and slowly absorbing this new world you have landed in, you wonder what lies ahead. The different vocab, the slang, the different cultures, the stories from other parents. Some were good, some were inspirational and some soul destroying.

You were encouraged to attend the Ministry of Education forums touring the country. The special education update. That was a first experience. You could understand some things. There were the naysayers and the moaners and you were surprised and encouraged by those that could articulate what they wanted in a future education model.

Then in 2016 with young Johnny now in the system, the results of this so called Special Education Update arrived. Brilliant, all good!

They said they held 156 meetings and met with 3,650 parents, whanau, young people, early childhood and school educators and other education professionals. They also told you special was a naughty word and would be replaced by learning support needs? Funny that, whenever you want to find out stuff about Johnny overseas you always look at special education this, special this and that?

ANYWAY THIS SPECIAL OOPS EDUCATION UPDATE TOLD YOU.

- Parents wanted to be heard and respected as active and equal participants in their child's learning.
- Parents and whanau want to be much better informed about the help available, and how to access it!
- Parents wanted easily understood information about their children's progress.
- Simplicity, transparency and availability matter. The information parents get about their child's progress and wellbeing being isn't always up to date or detailed. Parents felt the need for better data and to improve the quality of reporting.
- Parents liked the Ministry suggestion of a single point of contact to liaise with the child parents, whanau, teachers and others to plan and arrange additional learning support.
- The ministry also told us that many parents also see the need for an advocate to make sure they get continuity of service and that there is a good fit. The single point of contact

between the child, the parents, whanau, and anyone else on a child's support team.

- Oh and they also told us that the long awaited and collaborative approach to sorting out disputes between parents, school management and school boards of trustees would be just that! Collaborative! Whoopee! The collective parents come runneth over!

The plan was a pilot project in the Bay of Plenty to trial a collaborative service involving health, education and welfare connecting with kids in the 0-8 age group and continuity of a support coordinator, navigator, connector. That was in January 2017.

Brilliant! But how long does a pilot programme have to fly before someone says, "Great, let's roll this out"?

15 MONTHS ON IT REMAINS A PILOT!

The pilot parent engagement groups have been functioning in the Wellington region for over 18 months now with limited support, and limited success!

The much collaborated disputes resolution process is finally about to be piloted in three regions, Nelson, Manawatu and Auckland but not in the format anticipated or promised. The Ministry of Education have decided to be both judge and jury and the parents wonder whether the old system was more equitable.

So what do Johnny's parents know now? Well many things are on hold with the election of a new government. Tomorrow's schools which was introduced by Prime Minister Lange in 1987 is up for review. The government plan two education summit meetings in early May where many many people will be attending.

I wonder if Johnny's parents will be reflecting on those 156 meetings and 3,650 attendees and where are we? Will we have to wait another two years for the pilots to be ratified certified and ready to roll? So where will Johnny be in 2020? Well we know he will be 10! What we don't know is whether the promised intentions of the special education update will become a reality.

Maybe we as a parent group should be saying.

"THIS LONG IS TOO LONG".

NATIONAL ASSESSMENT SERVICE (HOMAI CAMPUS) BLIND AND LOW VISION EDUCATION NETWORK NZ

WHO IS BLENNZ?

The Blind and Low Vision Education Network NZ (BLENNZ) is a school that is made up of a national network of educational services for children and young people (ākongā) who are blind, deafblind and low vision.

OUR VISION IS:

Every BLENNZ learner is well prepared to achieve in life.

WHO CAN USE BLENNZ SERVICES?

- Ākongā who are blind, deafblind and low vision from birth to 21 years or to the end of their schooling
- Parents and whānau
- Teachers, teacher aides, education support workers and others involved in the education of ākongā

WHAT IS THE NATIONAL ASSESSMENT SERVICE (NAS) AT BLENNZ?

NAS is a team of education and health professionals, trained and experienced in the field of vision impairment and including ākongā with additional special needs. The service offers a comprehensive assessment of the vision and development of ākongā. The aim is to provide families and teaching teams with baseline and current information to support educational planning. NAS is based at BLENNZ Homai Campus in Manurewa, Auckland.

This service is available for ākongā on the BLENNZ roll from birth to 21 years, living anywhere in New Zealand. A detailed report and programme recommendations follow the assessment.

Assessments are carried out for two ākongā per week at Homai Campus, on a termly basis. Twice a year (usually March and September) the full team travels to a regional centre to carry out assessments. On average 10 ākongā will be seen by the full team at these visits with a few more being able to be seen by the ophthalmologist/optometrist and senior teachers with functional/sensory expertise.

WHO IS THE BLENNZ NAS TEAM:

COORDINATOR

The NAS coordinator is Sue Arrojado. The coordinator is also a key member of the BLENNZ leadership team in addition to her role coordinating the team below.

THE OPHTHALMOLOGIST (EYE DOCTOR)

The ophthalmologist undertakes a comprehensive eye examination and offers medical and diagnostic information.

THE OPTOMETRIST

The optometrist assesses visual acuities, the need for glasses and low vision aids.

MUSIC THERAPIST

The music therapist uses sound and music to assess functional, emotional, musical and creative abilities and needs.

PAEDIATRICIAN

The paediatrician undertakes a comprehensive medical check, offering advice on diagnosis and treatment.

For further information about BLENNZ services, visit our website at:
www.blennz.school.nz

NEW AUSTRALIAN CHARITY FOR CHILDREN AFFECTED BY CATARACT



A new charity, Cataract Kids Australia, has launched across the ditch. Led by Dr. Megan Prictor, a parent of a child affected by congenital cataract, the organisation was established in mid-2017 and recently had a very successful launch event in Melbourne. The organisation aims to: improve information and support provided to children affected by cataract and their families; work with clinicians to optimise treatment outcomes; and link with researchers to improve the integration of research into patient information and clinical care.

Cataract Kids Australia has set up a website, www.cataractkids.org.au, which includes clear and reliable information about the condition and its treatment, tips and tricks from families, a list of relevant events, links to the latest research, and stories about the cataract 'journey' written by parents from all around Australia. The website features stunning photography from Sarah Craven, a newsletter sign-up link, and an extensive glossary of important terms in plain language. The clinical information has all been reviewed for accuracy and clarity by clinicians and families.

Some of Cataract Kids Australia's early successes have included bringing together close to 100 families, clinicians and researchers for an event in Melbourne, and partnering with a Sydney stem cell scientist for an ABC News story on a new technology that could offer a revolutionary treatment option for childhood cataract - that story is here.

We are also active on Facebook and Twitter. We are keen to make connections with the childhood/congenital cataract field internationally, and with that in mind we were delighted to be contacted by Parents of Vision Impaired NZ. For more information about Cataract Kids Australia please visit our website, email info@cataractkids.org.au or phone Megan Prictor on +61 407885580. *Credit: Sarah Craven Photography*

CATARACT KIDS AUSTRALIA

www.cataractkids.org.au / info@cataractkids.org.au
Megan Prictor: +61 407 885 580.



PVINZ TEAM UP WITH ROYAL NEW ZEALAND BALLET

Good News!

PVINZ making history with the Royal New Zealand Ballet.

As a follow-on from 2017 where we were able to subsidise 25 of our vision impaired children and young people plus carers to audio described school matinee performance of the Romeo & Juliet ballet. We are thrilled to advise that the Royal New Zealand Ballet has expanded that programme into 2018.

PVINZ will provide **165 tickets** to *The Nutcracker* audio described school matinee performances being held across three centres: Auckland, Christchurch and Wellington.

WELLINGTON performance on Thursday 1 November, 12.30pm Opera House

CHRISTCHURCH performance on Friday 23 November, 12.30pm Isaac Theatre Royal

AUCKLAND performance on Friday 7 December, 12.30pm Civic Theatre

PRICES:

\$15 per student/teacher with a free companion ticket made available if required. Limited spaces.

Be sure to watch this brief video clip showing footage of last year's audio described performance by clicking here.

Due to the popularity of these events, seats are allocated on a first come, first served basis. Book now so you don't miss out!

FOR BOOKINGS

Please contact RNZB Education & Community Manager
Pascale Parenteau:
pascale@rnzb.org.nz / 04 381 9001

CLICK BELOW TO
VIEW THE VIDEO



rnzb | Education
ROYAL NEW ZEALAND BALLET

NEWS FLASH

CONFERENCE AND AGM 2018

TRANSITION AND RESOURCES

THE PATHWAY TO SUCCESS

26-28
OCTOBER

WEST PLAZA HOTEL
WELLINGTON

The PVINZ Conference will be held in Wellington: Friday 26 October (assemble), Saturday 27 October and Sunday 28 October 2018

VENUE: WEST PLAZA HOTEL,
Wakefield Street CBD

We are limited to 65 parent conference delegates, so it will be first in first served.

PVINZ WILL PAY FOR MEMBERS:

- Return air fares in New Zealand.
- Accommodation share twin West Plaza Hotel, Friday and Saturday night.
- Breakfast Saturday, Sunday. Lunch Saturday. Banquet dinner Saturday night.
- Parent delegate reg fee \$160 per couple.
- Parent delegate reg fee single \$80.
- Single with own room a supplement of \$40 per per day.

Friday night will be mix and mingle. The conference will start at 9am on the Saturday and conclude at 12pm on the Sunday.

For PVINZ members wishing to provide their own transport to attend only the Saturday programme, we will have limited space available.

For delegates attending from our partner organisations and professions we have a registration fee of \$120 per person. If attending the dinner an additional \$50 is required.



Parents of Vision Impaired (NZ) Inc

2018 PVI CONFERENCE REGISTRATION FORM

26-28 October 2018

ATTENDING PARENT - CAREGIVER/S DETAILS. PLEASE PRINT OR TYPE

Parent 1: (Last name)

(First name)

Parent 2: (Last name)

(First name)

Address:

Email Address:

Telephone:

Day

Evening

Mobile

Travel arrangements:

Air

Depart date

Depart Time

Air return

Depart date

Depart time

By Car

Car park required?

☐

Yes

☐

No

In order to secure cheaper air fares we need to register and book early.

ACCOMMODATION is on a share twin basis

Friday night meal is at your cost.

Friday night accommodation

☐ Yes☐ No

Saturday night accommodation

☐ Yes☐ No

The accommodation bookings will be made by PVINZ Inc, so please do not call the Hotel.

Friday + Saturday night accommodation

DAY PROGRAMME Saturday only

☐ Yes☐ No☐ Yes☐ No

CONFERENCE REGISTRATION COST is \$80 per parent delegate.

SPECIAL REQUESTS:

Diet:

MOBILITY Issues:

PARENT CONFIRMATION OF MEMBERSHIP:

I confirm my child

(Name of Child needed to confirm membership)

Has a serious vision impairment and that I am a registered parent / caregiver of Parents of Vision Impaired NZ Inc

SIGNED:

Please send this form to Parents of Vision Impaired NZ Inc, P O Box 513 Waikanae, 5025 or email to david@pvi.org.nz

For delegates attending from our partner organisations and professions we have a registration fee of \$120. Accommodation and travel is at your cost.

| SUMMARY | COST |
|---|------|
| Parent registration per couple: \$160 per couple | |
| Parent registration share twin: \$80 | |
| Parent single accommodation: \$40 per night | |
| Delegates partner organisation: \$120 | |
| Delegates partner organisation dinner: \$50 | |
| TOTAL | |

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WWW.PVI.ORG.NZ

NUMBERS ARE LIMITED SO PLEASE REPLY AS SOON AS POSSIBLE.

Deposit directly to our bank account ASB account # 123100 0115685 00.



CONTACT US

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