

eVision April 2020

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



PVINZ



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Contents

4

Chairpersons
Report 2020

5

Message from
the EO

6

Looking After
Others

7

Board &
Executive Office

8

Meet Elizabeth
from The Board

9

2020
Conference

10

Hand Sanitizer
Recipe

10

Social Media
Update

11

Snap Send
Solve

12

Psalm 46

13

Light Switches,
Secrets and
Single Stories:
Growing Up Blind

14

School Tips

15

Birthdays and
Social Connection

16

Focus on
Keratoconus

18

Visually Impaired in
Mvumi, Tanzania

Chairpersons Report 2020

Kia ora koutou,

Welcome to the first eVision for 2020 and all that it brings to the PVINZ Family.

Your Board have 'hit the ground running' with Zoom and Face to Face meetings as we plan our time ahead. Rebekah and I were invited to meet with John Mulka and Karen Stobbs in Auckland recently. Blind Low Vision NZ Aotearoa and BLENNZ are key partners in our organization and it was an opportunity to share thoughts and work towards a joint vision as we move forward. I feel that we are in exciting times, giving the opportunity for real change in providing the best possible services for our members.

4

Speaking of change and moving forward, Rebekah has transitioned to the role of Executive Officer with enthusiasm and professionalism. It is never easy taking on a role such as this and huge thanks from David in assisting in the smooth transition. As acknowledged at our 2019 conference, 'it will be a hard act to follow'. At the conference, we also welcomed two new members to the Board. Andrea Lamont and Elizabeth Manson. We have gelled well has a Team and both new members of the Board bring a unique set of skills.

2020 brings many challenges for your Board and will be met with careful thought using our Mission and Vision as our guiding principal. We have a lot of work to do ahead of our 2020 conference and look forward to giving updates to our PVI Family throughout the year. As always, we welcome feedback, ideas and suggestions from you – this is your organization. Please make use of our Facebook pages and our website to connect with one another.

Now sit, back, take the time and enjoy what we have to share in our E Vision.

Ngā manaakitanga

Judith

POSTSCRIPT

Since writing this Chair update, our country and communities have faced the challenge with the Covid -19 Level 4 announcement. These are challenging times ahead with families having to remain at home. We as a PVI Family face unique challenges with not having many of the formal supports in place. This is a time when we need to support each other, reach out and ask questions, seek ideas and assurances – it's OK. PVI is a safe and empathic space. Sometimes it is only us, that have that lived experience, really 'get it'. I urge you all to remember we are here for one another, use our Facebook page or contact us if you have concerns or just want to 'vent'!

KIA KAHA, NA JUDITH



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John Mulka, Rebekah Graham, Judith Hyslop, Karen Stobbs

Message from the EO

Welcome to the first e-Vision for 2020. It has been strange times indeed lately. By the time this reaches you, we will be well into Level 4 lockdown and I am sure you would have been inundated with COVID-19 emails and updates aplenty! This issue we have focussed on a variety of topics with the thought of providing something interesting and fun to read at this time.

I'm sure you all know this, but as PVI Board members - and as parents ourselves of vision-impaired children - we wanted to reiterate that we are very much here for all of you at this time (as much as we can be!). We are still here at the end of a phone, an email, a Facebook message, even a Zoom meeting (although I rather suspect

we are all going to be thoroughly sick of Zoom meetings by the end of four weeks!).

In case you don't have our contact details, all the Board members phone and email details are below. Also, if you haven't already, do join our Facebook group and introduce yourself at [facebook.com/groups/194420327255](https://www.facebook.com/groups/194420327255)

Once more, if you have any concerns at all - or even just feel like a chat - please don't wait for us to call you, do pick up the phone and say hello.

Take care and stay safe,
He waka eke noa,
Rebekah

Looking After Others

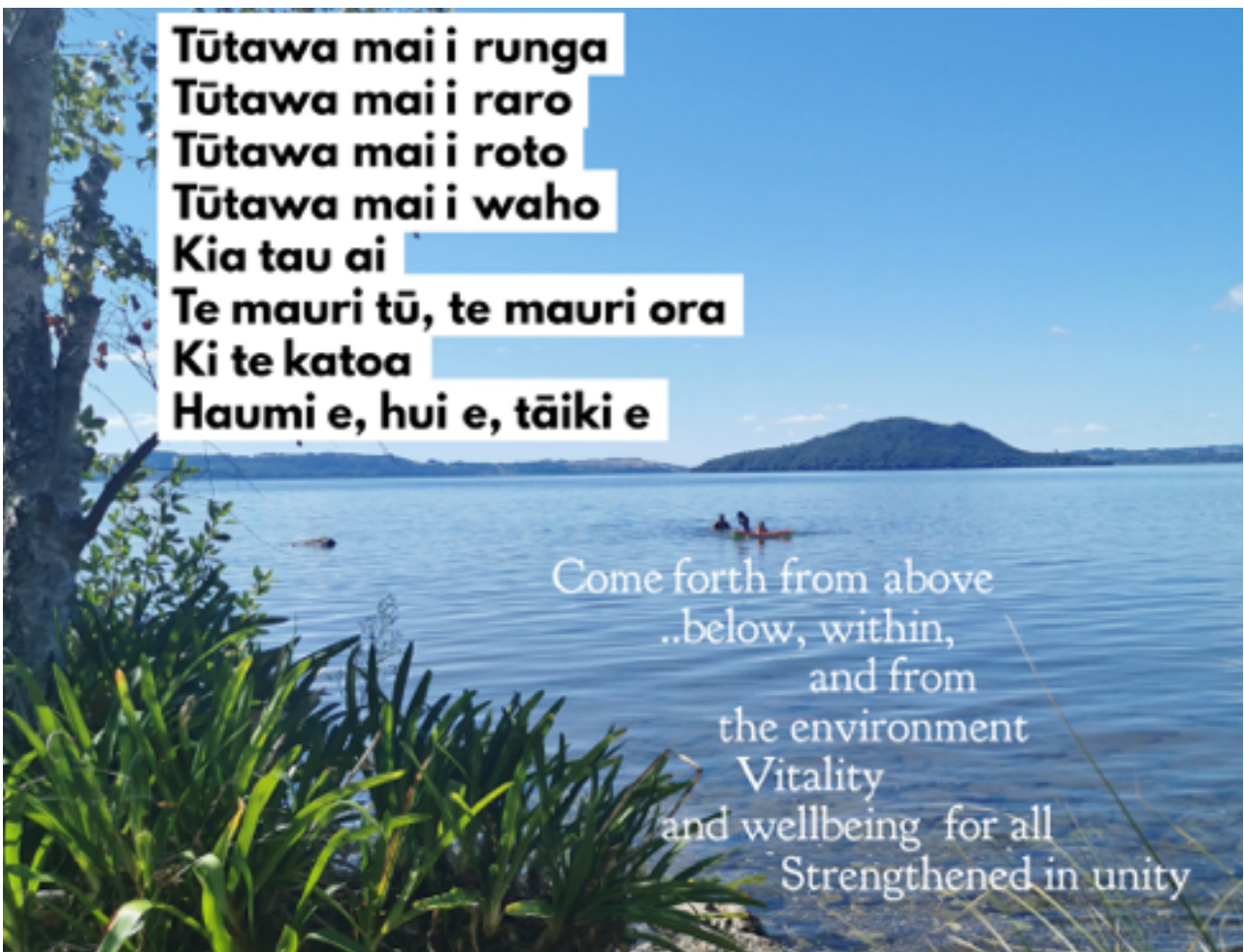
Kindness is an incredibly powerful way to make a difference. You can do this by:



- Checking in on older relatives or vulnerable people over the phone, to make sure they have everything they need.
- Talking to friends, whānau and neighbours over the phone to see how they are and if they need support.
- Dropping essential supplies, like food or medications, to those at home. You can leave them at the door.

These kinds of connections and offers of help will go a long way to getting all of us, together, through the next few months.

6



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Meet Elizabeth from The Board

Sam riding his mountain bike on holiday at Kaiteriteri

8

This issue we are highlighting Elizabeth Manson who is the PVI Upper South Island representative. New to the Board, Elizabeth lives in Christchurch where she works as a Practice Nurse in Primary Health. Elizabeth comments “I feel strongly that New Zealand needs to be accessible for all, and I love that PVI supports parents in the journey they are on. I love meeting other parents [at Conference] and hearing their stories but also feel that I get heard by people who just ‘get it’. An added bonus is that I get to have a weekend away with my husband!”

Elizabeth is married to Kevin and they have 3 sons: Ben 14 years, Sam 12 years and Tom 10 years. Elizabeth introduces Sam and their journey below:

As a baby Sam was very sensitive to light but it wasn't until we requested that he have his 4 year-old eye-check early that we discovered he had amblyopia (a lazy eye). He wore an eye patch daily for the next 2 years - sadly with little effect. Sam managed well and his vision was fairly stable. One day last year while at school Sam experienced a sudden and complete vision loss lasting several hours.

Soon after we were told that Sam was losing his sight. They call it “Progressive Inherited Macular

Dystrophy” but as yet we don't have an official diagnosis. We are still waiting for results of genetic testing.

Sam is now learning Braille and Jaws and working with an orientation and mobility specialist and we are all getting used to his new normal. Sam loves sports - especially mountain biking, swimming and athletics. The highlight of the past three years for Sam has been competing with Parafed Canterbury at the South Island Junior Games and the Halberg Games.

In the summer each year we go camping at Kaiteriteri in Tasman. Such a beautiful part of Aotearoa! The boys love swimming and mountain biking while I enjoy catching up on reading. This year both sets of grandparents joined us. Four years ago we returned to Zambia (where I worked for 5 years a nurse tutor in the early 2000s) for 7 months while our house was being rebuilt (it was damaged in the Christchurch earthquakes). We had a fabulous African adventure and are grateful for the wonderful memories that Sam and the other children have made.

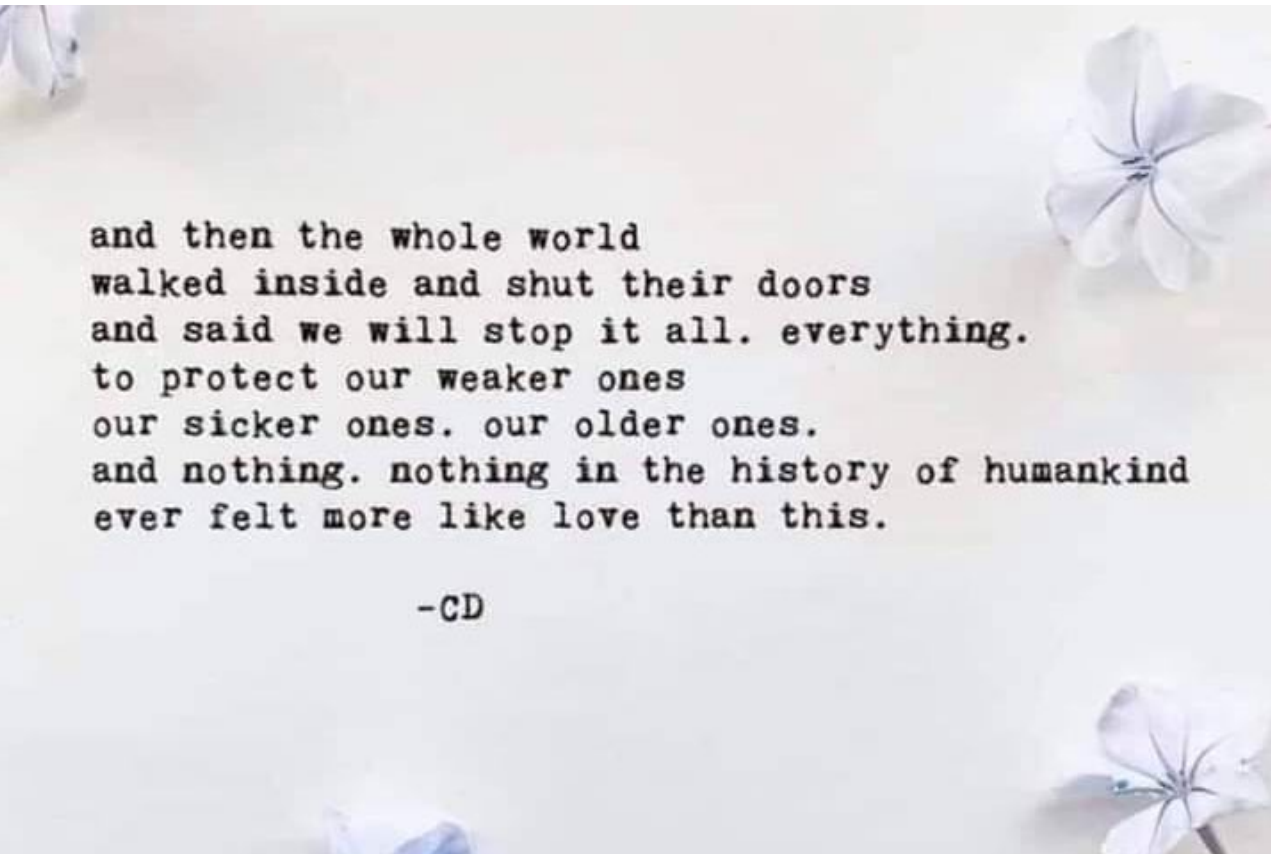
If you are in the Upper South Island region, Elizabeth would love to hear from you! You can contact her on tisch.manson@gmail.com

2020 Conference

We have set our PVINZ Conference dates for 2020. While there is some uncertainty going forward, we will continue to gently move ahead with Conference planning. Hopefully by October we will be back down to COVID Level 2 and able to have meetings of less than 100 people inside. To that end, please save

Friday 16 October – Sunday 18 October 2020

as the dates for our 2020 conference. We will keep you informed as the year progresses and as we have more certainty around being able to meet face-to-face, book travel, and continue to keep members safe.

A quote is displayed on a light, textured background. Several white, five-petaled flowers are scattered around the text, with one prominent flower in the upper right and another in the lower right. The text is in a typewriter-style font.

and then the whole world
walked inside and shut their doors
and said we will stop it all. everything.
to protect our weaker ones
our sicker ones. our older ones.
and nothing. nothing in the history of humankind
ever felt more like love than this.

-CD

Make Hand Sanitizer at Home

Mix together:

- * 60ml isopropyl alcohol
 - * 90ml aloe vera gel
 - * 20 drops tea tree oil
- And you are good to go!!

Social Media Update

Our Facebook group Parents of Vision Impaired (N.Z.) Incorporated, "P.V.I." continues to go great guns. With over 200 members it is a wonderful source of information, amusing anecdotes, support, and feedback. The nature of Facebook makes it an ideal site for gathering quick feedback on issues, and for sharing various items that members may or may not find useful and interesting. If you're not already a member you can search us up or click on the link: facebook.com/groups/194420327255

We also have a Facebook page. Like us on facebook.com/pvinz

I have started a Twitter account: [@PVI_NZ](https://twitter.com/PVI_NZ) is our handle and you can find us at twitter.com/PVI_NZ

Twitter is a fast-paced medium and the conversation can move quite quickly. Several journalists use Twitter to find breaking news and other items of public interest. Twitter is also useful for advocacy and publicly supporting the disability community on topics of relevance and interest – and is a handy way to connect with others in this space both in New Zealand and worldwide.

We may also have an Instagram account in the works! This should provide a more visual medium to promote who we are, what we do, and raise some awareness around blind, low-vision and vision-impaired children and their needs.

We are now on Twitter

Follow @PVI_NZ

TWEET HIGHLIGHTS

Top Tweet earned 1,529 impressions

Welcome to Parents of Vision Impaired (NZ). We are a registered charity and support parents who have blind or vision impaired child(ren). Come join a supportive community of parents who overcome challenges every day 😊👍
pvi.org.nz
[#PVINZ](#) [#Blind](#) [#VisionImpaired](#)

👤 4 ❤️ 11

Top mention earned 12 engagements



Karleigh-Jayne Jones

@Jonesy79_NZ · Jan 13

[@PVI_NZ](#) is on twitter, they provide support to parents of blind and low vision children twitter.com/BexGraham/stat...

👤 4 ❤️ 6

[View Tweet](#)

Snap Send Solve

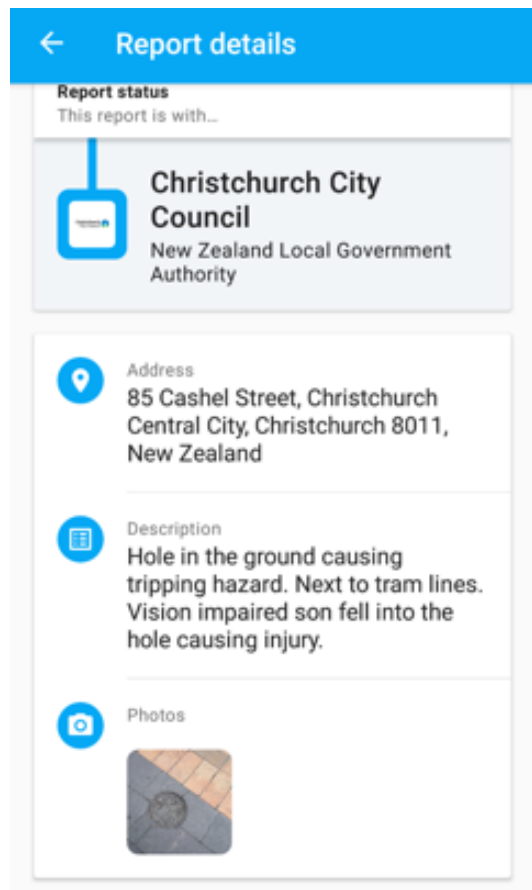
snapsendsolve.com

Snap Send Solve is a FREE website and app where you can immediately post an issue – parking on pavements, abandoned trolleys, dumped rubbish, poorly maintained crossing signals – whatever the issue you can Snap Send Solve it!!

Free to download from the App Store, Google Play, and available online, Snap Send Solve means you can report incidents on the spot! Take and send a photo of an issue that need attention - from cracked pavements to playgrounds to water faults – directly to the local authority responsible for maintaining it.

Snap Send Solve makes it easy to report on incidents and makes it easier and more efficient for local councils and other responsible authorities to act on the reports.

Board member Elizabeth Manson reported a tripping hazard spotted while out walking in Christchurch (see image) – and noted that it was promptly addressed within the following 24 hours. Success!



Psalm 46

God is our refuge and strength,
a very present help in trouble.

Therefore we will not fear, though the earth should change,
though the mountains shake in the heart of the sea;
though its waters roar and foam,
though the mountains tremble with its tumult.

There is a river whose streams make glad the city of God,
the holy habitation of the Most High.

God is in the midst of the city; it shall not be moved;
God will help it when the morning dawns.

The nations are in an uproar, the kingdoms totter;
he utters his voice, the earth melts.

The Lord of hosts is with us;
the God of Jacob is our refuge.

Come, behold the works of the Lord;
see what desolations he has brought on the earth.

He makes wars cease to the end of the earth;
he breaks the bow, and shatters the spear;
he burns the shields with fire.

'Be still, and know that I am God!
I am exalted among the nations,
I am exalted in the earth.'

The Lord of hosts is with us;
the God of Jacob is our refuge.

Amen



Light Switches, Secrets and Single Stories: Growing Up Blind

By Áine Kelly-Costello

As a kid, Aine knew that being blind was harder but never worse than being sighted. She wants to pass that knowledge on, but resists being a 'blind kid success story'.

I'm sitting in my pyjamas and favourite fleece in front of the computer in my student apartment in Gothenburg, Sweden. It's February and, though the sun has made some erratic appearances this week, shades of less dark, dark and darkest are still normal. The low light reminds me to take my vitamin D supplements. This winter, for the first time in my life, I've taken to turning on the electric light in my room. I'm pretty sure it helps my sleep cycle and, besides, I can see just enough light to remind me that Sweden really is much darker in winter than New Zealand, where I mainly grew up.

[Continue reading this story at pantograph-punch.com/post/Growing-Up-Blind](https://pantograph-punch.com/post/Growing-Up-Blind)

Shared with permission from The Pantograph Punch.

School Tips

We asked a standout school SENCO (Special Educational Needs Co-ordinator) what are some of the things that they have found useful for supporting vision-impaired students. Here is a short quick list of easy ideas, some of which are transferable for home learning as well:

- Organise a quiet and visually-calm area in the classroom for the student to move to if they are feeling overloaded. Some of our classrooms use a Tepee style tent, big cardboard box, library corner with pillows/cushions, beanbag etc. In this area there might be things to do/toys to help calm and soothe students. All students in the class benefit from an area like this - the odd new 5-year-old will fall asleep in these spaces if they are shattered!

14

- Timetable in sometime in every block for the child to have some time out of the classroom. It depends on the level of fatigue as to how often: it may be in class for 45 minutes then 15 minutes out of class with Teacher Aide. Time out of the class gives the student time away from the demands of the classroom, so they can de-escalate and regulate in order to manage well for the next teaching block (45 minutes).



Supporting student agency across the curriculum.
Source: BLENZ Learning Library



Positive rewards for positive behaviour. Winning!!

- Time with a Teacher Aide or Support Staff in the playground when the rest of the students are inside. This means that the child can learn and gain confidence on the playground without the hustle-bustle of other students.

- Playground and break time: give the student the option of going to the library/classroom (or another quiet place) with the Teacher Aide or an older student. Our students have the option of taking up a friend also (promotes positive social connections).

- Tuakana-teina relationship. A school mentoring programme, where the older students spend an hour or two each week mentoring younger students. Prepare the older student(s) so that they are aware of any needs and provide some structured activities (e.g. quiet reading in the tepee, playground familiarisation, using an iPad) to do together during this time.



Birthdays and Social Connection



^ The teepee is a popular reading and talking space.
Source: <https://www.stuff.co.nz/manawatu-standard/news/93168507/classroom-spaces-upgraded-created-for-new-learning-approach-at-awahou-school>



Don't forget that the TKI website is an excellent resource for teachers, students, and families alike. This site has all sorts of links and videos and pdfs specifically designed by and for educators to meet the needs of low-vision learners.

See www.inclusive.tki.org.nz/guides/low-vision-and-learning/



Justine Edwards is the PVI representative to Banzat ((Braille Authority of New Zealand Aotearoa Trust). Her daughter Giana uses a cane, learns Braille, and this year, started at a mainstream school for the first time. While not without challenges for the school and for Giana, it has brought new social connections, included being invited to celebrate a birthday with her newly-made school friends. Justine comments below:

“It was so lovely how inclusive the games were and the things the family thought of just so Giana could be included. A sign with English, Japanese, and Braille; the party box had Braille as well. The birthday girl decorated the gazebo with streamers so Giana knew where the edge of the party was; she decorated the washing line pole with sensory plants with different smells. The girls were all so good with Giana, it made my heart so happy.”

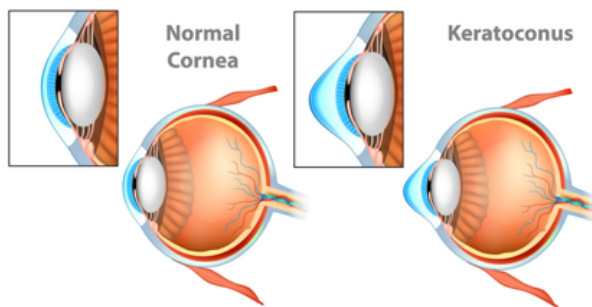
It makes our hearts happy too.

Focus on KERATOCONUS



You wouldn't believe it by looking at him, but this kid has Keratoconus

In March my (Rebekah) second child, Kenan underwent eye surgery. Kenan was diagnosed with keratoconus late last year, and the ophthalmologist recommended him for corneal cross-linking to prevent any further deterioration of his cornea (and vision). Turns out keratoconus is quite common in NZ, and, for reasons unknown, is not always picked up by optometrists. This issue I've included a brief outline on his eye condition – I hope to highlight an eye condition each issue and would love to hear from you regarding what eye conditions you would like highlighted in future issues.



Pronounced keh-rah-toe-cone-us, Keratoconus is an inherited eye condition that leads to reduced vision (even when wearing glasses or contact lenses). It usually develops between the ages of 10-25 years BUT is often diagnosed late (or not at all!) in New Zealand.

Keratoconus is a weakness in the cornea (the clear dome-shaped window at the front of your eye). The normal curvature of the cornea becomes distorted and a cone-shaped bulge develops. This causes irregular astigmatism and poor vision. People who have Keratoconus experience distortion of their vision including multiple images, sensitivity to light and streaking. Symptoms also include finding bright light uncomfortable, difficulty seeing in bright light, halos around lights especially at night, making night driving difficult. The amount of visual distortion varies between eyes as often one eye is usually more affected than the other.

We have a high prevalence of Keratoconus in New Zealand: a recent Wellington-based study estimated that it affects 1 in 191 non-Māori and 1 in 45 Māori adolescents. This study noted that Keratoconus appeared to be associated with Māori ethnicity, atopy, lower school decile, visual impairment, and the underutilization of visual aids. The authors recommended a nationwide screening program to reduce the “burden of disease associated with keratoconus” – which is a fancy way of saying, kids who can't see well end up with all sorts of hassles as school (like, they get bored, and play up, and are then seen as the 'naughty kid' instead of getting assessed for a vision issue) and this is worse for kids in impoverished areas.



Kenan post corneal cross-linking surgery, feeling grand

Treatment includes glasses, contact lenses, corneal cross-linking and corneal transplant. Corneal cross-linking is a surgical treatment used to stop the progression of keratoconus. Patients with advanced keratoconus that don't respond to corneal implants or corneal cross-linking may require a corneal transplant.

Sources and for additional information:
<https://boweneye.co.nz/bowen-eye-news/keratoconus>
https://journals.lww.com/corneajrnl/Abstract/2019/11000/Keratoconus_Prevalence_Among_High_School_Students.8.aspx
<https://www.aucklandeye.co.nz/about/blog/everything-you-need-to-know-about-keratoconus/>

Visually Impaired in Mvumi, Tanzania



Servicing the Perkins Brailleurs

18

Mvumi School Trust in Tanzania have a Visual Impairment Unit to support the education of visually impaired secondary school students.

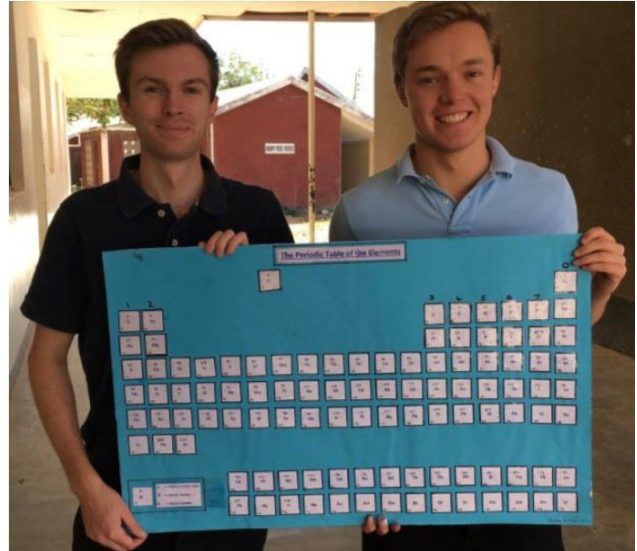
They currently have 25 students in the unit. The unit puts Mvumi at the forefront of top-quality and innovative education for the visually impaired in Tanzania. Blind and visually impaired students are sponsored by individuals so that they can receive a secondary school education.

The current school administrators are from New Zealand and have family members who are part of PVINZ. They have sent through some updates, anecdotes, and images regarding life in Mvumi and the Visually Impaired Unit.

The Mvumi School Trust is currently supporting the development of a technology room for Visually Impaired (VI) students. The first step is to create a room that impedes the ubiquitous red dust from coming in (the local area is renowned for this fine red dust which gets everywhere!).

The Head of the Visually Impaired unit, Mr Mbilu, is very skilled at servicing Perkins Brailleurs. He has taught other staff how to service the Brailleurs so that they can be put into use again.

Sometimes volunteers from the UK and other countries come to assist Mvumi School and the Visually Impaired Unit. They learn how to create Braille documents and produce Braille teaching resources.



LEFT - RIGHT: 1. Frederick learning how to service the Braille machines | 2. James and Mike with the Braille periodic table they created | 3. Volunteers hold a discussion with the VI students. | 4. Mr Mbilu, Head of VIU and School Trust representative Jane, and a local tradesman discuss the technology room requirements.

After their discussion, the volunteers (James and Mike) produced a Periodic Table in Braille for the VI unit. As you can see the Table is very carefully put together and is both a work of science and of art.

You can read more about the Mvumi School and the VI Unit here: mvumischooltrust.org.uk/the-school/visual-impairment-unit.html

EDIT: As with the rest of the world, Mvumi School is now closed until further notice. We are thankful that these stories were shared with us prior to closure and wish their Visually Impaired Unit all the best for the future.



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