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RI 2018 – Inspires New Hope.

For many people living with degenerative vision loss, the prospect of a cure or at least a treatment for their retinal disease might have seemed a long way off - perhaps not in their lifetime.

But for those attending the 2018 Retina International World Congress, it has inspired many to have a new sense of optimism, that treatments for their retinal disease might be just over the horizon.

There was cause for optimism on all fronts, with numerous clinical trials planned or underway in all of the six main research pathways; Transplantation, Artificial Vision, and Optogenetics, in situations where patients are blind because all or most of the photo-receptor cells are dead; and Neuro-protection, Antioxidants, and Gene Therapy in situations where some functional vision still exists, with the treatment objective to prolong the life of the remaining photo-receptor cells.

While it might be an uphill battle to get Pharmac to fully fund the US\$850,000 Luxturna Gene Therapy treatment, if a young adult met the criteria for this one-off treatment, how much more could they contribute to society over their lifetime? And more importantly, how much better would their quality of life be? Somewhere in a small room, there's an Economist with an abacus and a crystal ball, turning complex estimates into irrefutable answers to these questions on a DALY basis.

On a less scientific front, but similarly inspiring for those who attended, was the Retina NZ Youth Event which ran concurrently with the Congress from Wednesday to Friday. It brought young people from all over NZ and around the world, together in a range of social events, enabling them to share ideas and give inspiration and support to each other through shared experiences.

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Retina NZ Inc.

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From the Editor ...

Is it just me or does this year seem to be absolutely flying by? It hardly seems like we put Christmas and New Year to bed, then the Retina International World Congress and here we are, barely a Guinness away from Easter!

The conference was a great success on many levels, but for a lot of our members, its probably the first time they've been to a Retina Congress. Everyone seemed satisfied with the outcome, although there were a couple of people with hearing issues who found some of it a bit tough to hear at times.

With so many of our members able to attend the event we decided we'd get a number of different perspectives to give a real broad view of what the event meant to different people, what they got out of it etc.

We also hear from several from the younger fraternity who attended the youth event on the 3 days leading up to the conference proper. By all accounts it was a great success, everyone loved the activities that we'd organised for them.

For those of you who weren't able to go and are keen to learn more of the research progress that has been made over the last year or two, we will post a summary on our website, or you can email me and I will get one out to you in the appropriate format.

We've got a great story from Kathryn who's put the theories and practical ideas from the Low Vision Handbook into practice, in terms of contrast and lighting, when she did the whole

kitchen makeover recently, she's got RP but curiously she sees better with copious amounts of really blue light [6000 K], which is another point this story highlights that when you hear someone say this colour or that colour sunglasses or lighting is best for people with RP, its worth remembering Kathryn's example and going with whatever colour light works best for you and your eyes.

Peter tells us of his initial experiences with his new e-Sight wearable electronic magnifier. I had met a young Aussie guy in Melbourne in 2015 with a similar device to this, but back then he had to travel to Canada to get it fitted and his situation was similar to Peter's in that this device was paid for by a government agency that recognises it will enable him to continue to work in his chosen profession.

And finally a bit more technology Theres a new suite of apps from Novartis, in collaboration with Microsoft. Some of these apps have incorporated features from apps that are already in the marketplace, but the great thing with these is that they are FREE . Some are for low vision users and others are aimed at eye health professionals trying to explain the disease progression. I think they could be a useful tool for patients themselves to share with friends and family to give more insight into their eye disorder and how it might progress.

Enjoy the read
Mike Smith
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From the President ...

It has been a wonderful and busy start to 2018 for Retina New Zealand, with us being the host country for the 2018 Retina International World Congress held in Auckland in February.

My special thanks go to Professor Andrea Vincent for securing the amazing international speakers and to Fraser Alexander for the organisation of this special event.

It was interesting to hear of all the developments in research and clinical trials and the work that is being done to find a cure for so many different eye conditions. The highlight for me was getting to meet so many of our members and being able to talk about our similar issues.

Retina had a display stand in the Exhibitors area and I ended up spending most of my time there as we had so many enquiries about practical assistance and coping skills.

It brought home to me yet again the importance of Peer Support and practical advice. An example of this was parents of a young man who has severe night blindness being advised to get night vision goggles for their son. Even if they could afford them I really couldn't imagine a young man going out with his friends with something that big on his head!

I suggested a high-lumen small headlight he could put in his pocket and bring out when he really needed it, most likely when alone trying to navigate getting home.

People often try and be helpful for us and to us, but I really have found the best help for me has come from other Low Vision people.

Anyone who knows me will tell you I am technologically challenged and I admit this freely. I have learnt to do what I have to with a computer and cell phone but I see them as a tool, no different to a kitchen aid.

I realise many of you are in a similar situation and please don't ever feel pressured when told to "look online". I have found people very helpful when you explain you are Vision Impaired.

More businesses are starting to realise that they need to provide personal service if they are going to compete with internet shopping.

I hope lessons have been learned from the Census and that more information is made available early on so people can make informed choices.

Not everyone listens to the radio or television, has access to a computer or can read print.

Please remember we are always here if you would like to talk to us or find out more about anything you read in the Newsletter. The committee is here to help you in any way we can; phone 0800 569849.

Sue Emirali
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RI2018 – Member's Perspectives

Micah Rapata

Tena koutou katoa, Ko Micah taku ingoa. I am a 5th year medical student and had the privilege of attending the 20th Retina International World Congress. I am interested in ophthalmology as a potential career path, hence my desire to attend this conference.

I had previously completed research in the field of inherited retinal dystrophies and I was excited to see a significant part of the conference was devoted to addressing the latest research innovations in the treatment & management of these dystrophies. It was also great to hear that the first USFDA-approved gene therapy had been approved for retinal dystrophy caused by the RPE65 gene.

This conference was very unique in that it was not only for clinicians, but for patients and their caregivers as well. This was a new experience for me as I have never been to such a conference where this was the case. It significantly changed the dynamic of the conference and meant many of the addresses had to be digestible to both the patients and lay person, but also scientifically stimulating for the clinicians and scientists in attendance. I felt the conference speakers did a marvellous job of balancing the two.

It was also great to see the patients and the clinicians interact. From my observation it felt like the patients left with a far greater understanding of their disease aetiology, pathogenesis, investigations and treatments. I got the feeling that previously, many patients

had felt frustrated with the lack of treatment development and progress. However, as the world renowned researchers explained the complex process of research to the patients, they were more accepting, and understanding of the perceived slow progress in treatment development for inherited retinal dystrophies.

I would definitely recommend people to attend this type of conference in the future; whether you are a caregiver, a patient with a retinal dystrophy, a researcher or a clinician interested in retinal dystrophies.

Mary Butler

I'm an occupational therapist, so I was looking for particular things from the Retina conference, held at the University of Auckland. At an organisational level the conference was as good as any I've experienced.

There was an army of volunteer guides, ensuring that nobody with a disability missed out on anything. Eighty year olds were treated with respect by world class researchers who were kind and generous with their time. I might not have understood much of the science, but I was inspired by the passion of the speakers and the drive to find safe and effective treatments for people with low vision.

Intellectual generosity was a key theme of the conference for me and the drive to communicate complex ideas to a diverse audience. The presentations were about gene therapy, stem cell research, brain implants, optogenetics,

retinal implants, neurotrophics, antioxidants, neuroprotection and electrical stimulation of the retina. The speakers were world class researchers, who were genuinely aiming to communicate the science to clients, for example describing genes as matchsticks. They described some amazing advances in the field, including the first gene therapy for a specific retinal condition which has been approved by the FDA in the US (currently costing around \$850,000).

It was great to hear speakers talk about the importance of OT for helping people to integrate artificial vision aids into their everyday lives. For example a wearable magnifier has just arrived in NZ, which is being funded by WorkBridge. It costs \$18,000 and looks a bit like Jordy in Star Trek (<https://www.digitaltrends.com/wearables/esight-smart-glasses-blind-amazing/>). It's one thing to get a magnifier this sophisticated, and another thing to figure out how it can be used effectively in everyday life, which is where the OT might come in.

A speaker that made a huge impact on me was Pamela Gow, who described the journey that the low vision community in Canada has taken, over the last three years. They developed a strategy, where they hammered home a series of messages about;

- a) the need for vision rehabilitation;
- b) the risks to people if they don't have vision rehabilitation;
- c) the fact that it is the government's responsibility; and
- d) the fact that investment reduces costs in the long run.

Pamela spoke highly about the work of Occupational Therapists (OT's). For example, the Canadian version of the Blind Foundation (CNIB) uses the Canadian Occupational Performance Measure as their main outcome measure. They employ OT's by preference and constantly host OT students on placement.

One of the most inspiring talks was by a couple of parents - fathers, who spoke about the journey of their children and the whole family. They reminded me that determination is necessary for self-determination.

At the equipment stalls I learned about "Connect 12" from HumanWare, which is the best low vision device for students that I've encountered. The Connect 12 gives near and far (whiteboard) magnification, combined in a 12 inch android tablet. OT's are recommending it for tertiary students around the country and it's being funded by Workbridge. (<http://store.humanware.com/nz/connect-12-electronic-magnifier-new-generation.html>).

I was reminded of the importance of the simple things, for example;

- how much vision is enhanced by diet, exercise and living without stress;
- the need to try to understand what people 'see' and 'do not see';
- the need to understand visual conditions, like cataracts, dry eye, or other complications.

All in all it was a great event and one that I will remember.

RI 2018 - In Review

RON McCOLL

– Retina NZ Founding Member

I was fortunate to be able to attend the RI2018 Conference last month. The venue, Auckland University Business School, was generally adequate but its designers definitely did not have the visually impaired in mind. Some work had been done to assist orientation but had it not been for the plentiful supply of well trained volunteers it could have been difficult.

The programme was full-on and for a layman like myself a lot was over my head. However it was easy to be caught up in the enthusiasm of some of the top experts in their field. I found the second day especially interesting as the speakers demonstrated the ways that their amazing work was being used to bring practical benefits to the blind. I think New Zealand was honoured to have been awarded this conference and I am sure that anyone who can make it to Iceland in 2020 will not be disappointed.

ANN GRAY – Retina NZ Member

Attending the weekend of the Retina International Congress 2018 held in Auckland, was certainly an amazing and momentous experience that I will not forget. To hear and learn of the present research, and potential trials becoming possible, was truly of great interest to myself but also to help others in the family with the same condition.

I have Sorsby's fundus dystrophy which is one of the diseases Dr Alex Hewitt from Australia is doing research on.

I have relatives in Australia who have the disease and upon chatting with Dr. Hewitt we realised that they had participated in his research work. I was so pleased I got to speak to him.

There was one time when for a minute I was by myself, when a lady came over and asked me what my disease was, She was a lecturer at the ophthalmology department at the University. We had a good brief chat.

Everyone was generous with their time and I was very impressed with the support given by the many volunteers who were so obliging and kind.

MARK DE NIJS – Retina NZ Member

At Retina 2018, I learnt more in 2 days than 40+ years of having to go for eye check-ups at the eye hospital. I didn't realise how many different eye diseases there were and the 260+ different genes that are effected. Based on what I was told, I thought there was no hope for a retinitis pigmentosa treatment. This Conference has reopened my mind and made me more positive about the future of eye treatments.

The advances in technology are rapid and the very talented people in the world looking for safe effective treatments will hopefully enable vision impaired people to have a better quality of life.

It was exciting to hear that gene therapy has been successful in two gene mutations although is still in early stages but a very promising future. Although stem cell treatment is in early

stages it can now be possible to take a skin cell from your own body and that once it has been cultured in the lab it could be used to treat your retina (less chance of rejection). All the speakers talked about the importance of safety first with all clinical tests and treatments.

Having a healthy diet and living a good lifestyle also benefits most eye conditions and wearing sunglasses will protect your eyes from damaging UV. Using technology was also encouraged especially smartphone apps. I had a fantastic weekend and got to meet some really great people.

RETINA YOUTH

David Cumming

I was lucky enough to attend the Retina World Congress 2018 in Auckland. Along with this, I had the opportunity to attend and help to coordinate an amazing Retina NZ Youth Event which attracted youth from all around the globe as well as a great turn out from all over Aotearoa.

The youth event allowed me to meet a rambunctious group of inspirational individuals from the likes of Germany, Switzerland, the Netherlands, Australia and many other far flung regions of the planet.

We spent two days on a mission around Auckland; shredding gnarly surf at Piha, tramping through lush native bush with expert guides, cuddling puppies and sharing tales of embarrassing blind moments over a few drinks. The energy amongst the

group was incredible - it was a truly awesome experience to help our international guests see the sights and sounds of the stunning place we call home.

Even though we managed to fit all of these fun-filled events in to our time in Auckland, the highlight for me was having the chance to listen to two speakers over lunch on Friday.

Mary Fisher spoke to her sporting accomplishments at the Olympic Games, inspiring each and every person in the room. Then, Melanie Chatfield spoke regarding the under-discussed topic of the toll retinal disorders can take on mental health. In a world of remarkable research developments and technical vision aids, it is easy to overlook this aspect of living with RP. I think her speech resonated with all who listened. I hope that all of the youth members were able to take away from this, that there is always a support network around them if they need one. The event was simple yet stood out amongst a series of great moments over the length of the event.

Over the course of the weekend, I felt very lucky to hear from some of the world's leading scientists in the field of retinal disease. While the information was exhausting to absorb at some moments, the research developments have come such a long way since I was first diagnosed 10 years ago. I found the research on CRISPR technology to be mind-bogglingly exciting and the gene therapy trials and FDA approval timelines to be promising. The conference was well co-ordinated and

RI 2018 - Youth Review

the speakers of a high calibre. I will certainly aim to be a part of the 2020 World Congress and am already tingling with excitement at the thought of drinking Icelandic beer through the white nights, surrounded by my newly introduced international homies.

Karley Bergerson

I thoroughly enjoyed my time at the Youth event and at the RI conference. I am very grateful for the experience, I learnt a lot.

I absolutely loved the Youth event! This was my first time attending an event with other people who have low vision. It was very inspirational getting to know strong individuals from all around the world. We all felt very comfortable around one another to share our stories and learn how to overcome challenges that we all face on a regular basis.

The activities planned could not have been better. We went to the Guide

Dog centre, bush walk and surfing at Piha beach and went to a marae. These events provided a rich experience to those who had never been to our beautiful country before.

The conference was very well organised. Volunteers were so helpful and kind which made asking for assistance less confronting.

I particularly enjoyed the Independence and Self-determination session. Hearing the experiences of parents and low vision professionals was invaluable. Learning that independence cannot happen without interdependence and that people with low vision need to get digital to be ahead.

"Don't try keep up , just leap ahead" has been my motto since attending the conference. This was said by one of the parents in the session. In the programme, there was only one parent speaker listed, (Tim Corbett) but I am sure there was another parent

speaker. I would like to thank him for his talk, it was one of the most amazing sessions.

I feel like I have made some genuine connections. It was an honour to attend the Youth event and the RI2018 conference.

[end]



My New RP-Friendly Kitchen

by Kathryn

So, anything is going to be better than the 1963 kitchen which came with the house when I bought it 18 years ago, but what do I really want?

More importantly, I am not doing this upgrade to sell the house so I focussed on how I could future-proof the outcome for where RP might take me in the next 20 years - you can tell I'm not one to update until it is necessary!

I am not currently eligible for help from the Blind Foundation, so where do you suppose I might go to find the answers?

The best answer I can give you is talk to people. Gems of wisdom came from a fully sighted person who had just completed their own upgrade, from elderly people in a retirement village, some from past things mentioned in this newsletter and in the Low Vision Handbook, and from picking the brains of several fellow RP's about their dream kitchen.

Looking at images of kitchens online was a good way of testing some of their theories and after much googling there was also some freely available advice from other International Blind Foundations - such as RNIB in the UK.

Anything flat-pack or pre-formed gave little or no flexibility, so this ruled out the hardware-store-type option.

I met with three companies; a small family joinery business, a much bigger franchised joinery business and a franchised kitchen company.

It became apparent very quickly that only one of the designers was prepared to listen, rather than build to the norm.

So, my lovely designer and I began an adventure - she had designed kitchens for disabled people before, but never with the visually impaired in mind.

By this stage I knew a lot of what I wanted but she had ideas as well and more importantly was prepared to listen and go out and look for alternate options.

So where have I ended up:

Except for 2 overhead cupboards and the sink, everything else is drawers. The accessibility and availability of getting light to see what is in the drawers is FABULOUS. No crawling on hands and knees to find what is in the back of cupboards. Even the pantry which is shelves from waist height up has 2 pull-out drawers at the bottom.

Everything is matt finish - bench top, cabinet fronts, even the glass splash back (after much searching - I could see them available overseas but they are very new into NZ) so there is no issue of glare. Also, everything is contrasting colour - light against dark.

The floor was the joy of the project as beautiful Rimu floorboards hidden below old carpet and lino was a very happy surprise. So from the floor up we start with Rimu floor, dark grey kick plates, silver grey cabinets with dark grey door handles, then dark grey with marble effect laminate benchtop,

Member's Story

followed by a sea blue/green non-reflective glass backsplash leading up to pale grey walls. (Also, not one for zany in-fashion colour schemes so this is meant to be timeless - just in case you think it is boring).

Appliances are all set at waist height - oven door and dish washer (tall drawer) so that if you walk into an open door you have some hope of keeping your balance and avoiding an painful accident.

Try and find stores that have working versions of the appliances you are purchasing. I spent money on an oven with way too many bells and whistles, but it has a safety shelf system where you can pull a shelf and dish fully out of the oven without lifting it off the shelf and the shelf supports the weight while you turn/baste. No chance of over extending the slide and tipping the dish over yourself.

It also comes with two 3x10 inch lighting panels - one on each side of the oven, and a very simple two nob operation system with recognition of large symbols as function choice.

Many different makes had ridiculous numbers of buttons, or very small writing as the only means of operation. The temperature is displayed in 1 cm high large red numbers.

Make sure you fiddle with all the buttons and see what works for you.

The hardest thing to achieve was the different coloured shelves in the cupboards and pantry.

You can imagine the white plate, white shelf, white cupboard issue. So eventually my designer managed to convince the manufacturer that we were not insane and that we did indeed mean we wanted mid dark grey shelves with same coloured facing. They admitted it was no harder to make or more expensive it was just not what was usually asked for.

Lights. Any one who knows me knows I love a good light bulb. The bluer the better. I know blue light doesn't suit or work for all RP's but for me 6000 Kelvin is heaven. Going from one chinaman's hat in the centre of the kitchen; now the whole neighbourhood can read clearly when I turn the kitchen lights on! It is a galley kitchen which is now switched from both ends. Who wants to stumble through the kitchen in the dark to get to the light switch at the other end?

I have two 6000 Kelvin LED button lights as general light, a set of 4 LED spotlights also 6000 Kelvin over the sink and bench area, and expensive but worth every penny - I paid to have LED strip lights routed into both sides of the pantry with a pressure switch turning them on when the door is opened.

Yes, you could be mistaken for thinking someone is taking an x-ray, but I can see to read things that I would not normally be able to.

After a few hiccups along the way with the builder and of course taking longer and costing more than you begin thinking it will cost, I am VERY happy with the finished product.

E-Sight: A new user's review

by Peter Allen

I recently purchased an eSight Wearable Magnifier from Naomi Meltzer at Low Vision Services in Auckland. This is my story so far; first impressions, challenges to overcome and how this device will enable me to continue working in my chosen field, as well as assist with aspects of daily living.

My Story

I'm 53, I have RP, and have worked for a government agency in a computer based logistics analyst role for the last nine years. RP is a degenerative eye disease and the impact of my vision loss over these last nine years has been substantial. My work colleagues and managers have been tremendously supportive and helpful.

Because of security implications, much of the software available for low vision users cannot be loaded onto the CITRIX computer network (server based applications).

The only magnification software I can use with CITRIX, is the standard Windows built-in accessibility options, which have previously worked well for me.

Now that I use the full screen magnification option, my challenge is how I train other staff on their PC. At my desk is a black on yellow large character keyboard, 32 inch screen and Windows magnifier with inverted colour. I cannot use this setup at other people's workspaces.

Looking at the options

Five years ago, with funding from Workbridge, I bought a handheld magnifier. This was certainly helpful however clumsy and cumbersome when wanting to use a keyboard and view the screen simultaneously.

Similar issues when using a smart phone camera. My clip-on glasses magnifier was not powerful enough and users of lens magnifiers understand, the focal point is between 20 to 40 cm from the subject.

I could not look over PC operator's shoulders at their screens, I had to hang over them to get close enough for lens magnifiers to be effective - not really a suitable solution.

eSight

An RP colleague I had discussed my problems with, advised me of the electronic wearable magnifier options that had been on the market overseas for some time. After reviewing some of the models on the internet I looked to purchase one using Workbridge funding.

It was then I discovered they only fund equipment physically sold in New Zealand and therefore buying from overseas would need to be a personal purchase.

After a few phone calls I discovered Low Vision Services had just started importing the eSight two weeks earlier - it seemed to be a sign.

Assistive Devices

One of the reviews I read was a Top 10 Gadgets of 2017 by Time magazine.

I planned a visit from Palmerston North to Low Vision Services in Auckland, for a consultation and trial of the eSight.

I was impressed with the magnifier and some of the functions that enabled spatial orientation and the 24-times magnification. I could read "normal" print and my hands were free.

After receiving my application a few weeks before Christmas the staff at Workbridge quickly processed my application under the category of maintaining employment.

Within a week I had my full annual entitlement available to purchase the eSight.



Practical Applications

I was able to get my eSight while I was in Auckland for the 2018 Retina International World Congress. This enabled me to use the eSight while attending presentations in large lecture theatres.

I chose to sit at the back. It was very pleasing to sit so far from the presenter and screen and be able to read the presentation and also see the presenters face.

When your sight is cloudy, over-exposed blurry images, to see a person's face clearly from a distance and to read expressions and body language was tremendously uplifting. So used in this context the eSight was a considerable improvement.

When using my smartphone or iPad, I would use my lens magnifier and still squint. The eSight made it easy to read, however there were some coordination issues such as eye hand connection and depth perception. Seeing the text messages was easy, being able to select icons, buttons and keys on-screen while magnified takes a lot of practice and patience.

There were also some alignment issues with the prescription lens and magnifier when looking down; I would get double vision. Naomi advised some minor tweaking with the included Allen key and width adapter could improve that flaw.

[continued pg13]

When using an electronic magnifier (HD camera in the centre of the unit) that projects an image onto a screen (an LED screen on each lens) the size of the field of vision becomes restrictive. So using your head to scan becomes imperative, however constant head movement is a challenge.

Stability of the magnifier is achieved with two straps. One rubber strap attached to the unit and sits over the forehead. A second strap that connects with both a tiny ball on each of the stems and the detachable strap that goes behind the head, has a corresponding catch - similar to a tow-ball and trailer. These balls and catch's are also magnetised.

The double strap takes a little getting used to although there is no weight on the bridge of the nose. It takes trial and error to find the right strap tension, and even then you find that the unit does still move a little. Again something you get used to and although initially annoying, I got over it.

Summary

Using it to view a "normal" PC screen takes much practice and patience with trial and error efforts when typing.

The major difficulty is orientation when operating using magnification - I will need to improve my touch typing keyboard skills as it is the need to look away from the screen that creates disorientation. I am also playing with mouse and cursor control as that is another orientation challenge.

Does it offer a solution - for me yes I believe it will, it just takes some adjustments and modifying the way I do things as well as developing other skills.

The bottom line - it is wonderful to be mobile and read a normal screen again.

Editor's note: An Occupational Therapist might be of help when learning to do daily tasks differently, or for habilitation to a new device. It might be possible to include such costs in your application if you are seeking funding for a device.

Follow Retina New Zealand on Facebook & Twitter

Retina NZ has recently launched itself into the world of social media. If you're still using smoke signals don't worry, we'll always keep our 0800 numbers, face-to-face support groups, as well as public meetings.

We now have Twitter accounts for [Retina New Zealand](#), [Retina NZ Inc.](#) and [Retina Youth](#) these will mostly be for notifications or brief info, then readers will be directed to the Facebook pages for more info.

The Facebook Page is [Retina NZ](#), this will be mostly used for announcements or information from Retina NZ. We also have 2 groups; an open group called [Retina NZ Supporters Group](#) which is where members can share info and ideas with each other, while the [Peer Support Group](#) is a closed page where members can join to discuss things in private. We have a new [Retina Youth](#) page for general youth info, plus we also continue to run a closed group for [Retina Youth peer support](#).

Understanding Vision Loss

On the 1st of March 2018 the School of Optometry and Vision Science at the University of Auckland held a day for the 5th Year Optometry students on the topic of Low Vision.

The purpose of the day was to increase knowledge and awareness of the difficulties that people with reduced vision have to face.

Volunteers shared their experiences of vision loss and answered questions during the panel discussion. Katie Webber the Blind Foundation counsellor shared how Optometrists can improve their communication and manner when interacting with people with reduced vision.

Samantha Simkin, a PHD candidate at the UoA and Optometrist for BLENNZ explained the services BLENNZ provide.

Mid-morning the Optometry students got a hands-on experience of the technology to assist people who are blind or have low vision, during a workshop run by Adaptive technology instructors from the Blind Foundation. The students learnt about how technology such as iPads, cell phones and computers can be adapted to make them more accessible for people with visual impairments.

The students accepted the challenge of being blindfolded and correctly guided up and down stairs and to sit in a chair, after being shown the sighted guide technique by the Blind Foundation's Orientation & Mobility Instructors.

In the afternoon volunteer people with low vision and visual impairments kindly gave up their time to participate in some vision checking such as measurements of their central and peripheral vision and checking their prescription.

The Optometry students learnt a lot from the volunteers sharing their experiences and answering questions on daily tasks such as reading, cooking food and walking around.

The School of Optometry and Vision Science would like to thank all the wonderful people that were involved in the Low Vision day.

Thank you to the wonderful support from the Blind Foundation and BLENNZ. Thank you to Macular Degeneration and Retina NZ and to all the volunteers who kindly gave up their time to talk to the Optometry students and participate in some vision testing.

Another Low Vision day at the School of Optometry and Vision Science at the University of Grafton Campus is being held in March 2019.

We will be seeking volunteers with low vision and vision impairments to participate for 2 hours with breaks and afternoon tea included.

I would be delighted to hear from anyone who may be interested. Please contact me: Michelle O'Hanlon, Phone: 09 923 6592, or Email: m.ohanlon@auckland.ac.nz

Novartis launches ViaOpta apps

Most of us would have heard of Novartis, the big Swiss pharmaceutical company, but what you might not realise is that for some years now they have partnered with Microsoft to create apps for the healthcare industry, predominantly in oncology, but more recently in the field of eye health.

The "Via Opta" suite of apps is actually five separate apps; three of which are designed to be used by people who are blind or visually impaired, while the other two are aimed at eye health professionals to help patients understand how their disease might progress, but it could also be used by the patient themselves when they are trying to explain to friends and family how things look through their eyes. The 5 apps are;

- Eye Life - a series of videos which each describe a specific eye condition.
- ViaOpta Sim - vision simulation tool.
- ViaOpta Daily - a collection of 10 functions to assist with daily living.
- ViaOpta Nav - A navigational tool.
- ViaOpta Hello - a personal assistant.

ViaOpta Eyelife

The Novartis EyeLife app is a container app for Lucentis immersive experiences. The app provides 360° video immersive experiences for Living with Diabetic Macular Edema [DME], Myopic Choroidal Neovascularisation [MCNV], and Retinal Vein Occlusion [RVO]. Once downloaded, users can view the app in Flat or Cardboard View. Flat provides a film experience that is best viewed in

the user's hand, as you might normally watch a video on a smartphone.

Cardboard view allows the user to insert their phone into a cardboard viewer allowing a more immersive 360° experience, similar to that achieved with an Oculus headset.

ViaOpta Sim

While similar to the Eyelife, the ViaOpta Sim app offers "Live View" which uses the smartphone camera and augments the view with whichever eye condition has been selected. There is also a slider to adjust the severity. There are eleven options; Normal, Dry AMD, Central RVO, Wet AMD, Branch RVO, MCNV, Diabetic Retinopathy, Vitreo-Macular Traction, DME, Glaucoma and Cataracts. This will be an excellent tool for raising awareness.

ViaOpta Daily

ViaOptaDaily is a multi tool application that can help blind or visually impaired people in their everyday life. It uses voice guide and every section has an audible tutorial. Users can use it in various contrast modes, or in blind mode alike. It incorporates 6 main functions, but in all there are 10 options.

The symbols are very easily identifiable with large print and symbol on each button as well as contrasting colours for each button. The screen displays four buttons on the top two thirds of the screen and along the bottom are left and right navigation keys, and in the centre there is a menu key which allows you to edit and rearrange the buttons to your liking, so you can put all your favourite functions on the first screen.

Technology

While most of these apps already exist in one format or another, via OPta Daily app, puts them all together in an easy to manage toolbox:

- **WEATHER** (current and 3 day's forecast) - I found this a bit basic compared to what I'm used to. It does not tell me the suburb or city, and it has a quirky feature that if the forecast is for rain it makes the noise of rain falling and if the forecast is for sunny weather, it makes the noise of birds tweeting. The temperature is shown in both Celsius and Fahrenheit along with a picture of either a cloud or sun, but the audio description is not very comprehensive for example today it says 18°C and moderate rain. But for many people who aren't weather nerds like I am, they might find that it gives them the basic information they require.
- **MAGNIFIER** - for me this was one of my favourite functions, having been frustrated with many of these type of apps in the past where they want access to your contacts and other information in your phone which there is no reason for them to need, so this was a pleasant surprise and one that works really well. Previously, I have used the camera on my iPhone and taken the photo and then use my fingers to enlarge on the screen so I can see what I was looking at. There is a slider at the bottom of the screen which allows you to adjust the amount of magnification you require. Once you have identified what you want to look at you can simply touch the screen and it will take a freeze-frame picture, which you can further enlarge with the magnification slider. Then as soon as you touch the back button the picture disappears and is not saved, so unlike the camera, you won't end up with folders full of random pictures to delete.
- **COLOUR** - This speaks aloud the colour of whatever you are pointing the camera at. It works pretty well in daylight or good consistent light, but not so well in poor lighting. I tested it with 6 black socks which have dark blue, light grey or yellow colour coded heels & toes [sold at K-mart]. With my eyes closed, I held the sock on the palm of my hand with the coloured toe-piece by my fingertips. I held the camera to the palm of my hand where it spoke "black", then I slowly moved it up until it spoke the colour of the toe it got 6 from 6 correct. It might not have the sensitivity to tell if your socks were slightly different shades of black or dark grey .
- **TIMER** - this function might be really useful on a phone that didn't have SIRI or Cortana or any other Voice assistant. To set a timer, you scroll through Dial wheel to select the time and it reads out to you much like I talking clock. Personally I would just ask Siri to set a timer for 15 minutes. If discretion is preferred over the need for expediency then this app might work well for you.
- **CONTACTS** - This app gives you the ability to access your contacts in a large-print, accessible format. You could add unique ring tones, but nothing that isn't already available in most phones.

- **MONEY** - recognises US Dollars, Euros, REAL [Brazilian?], and LYRA [presumably Italian LIRA]. I am unable to test this, but I understand the US currency is difficult for vision impaired people to identify, so it may be of use to kiwis travelling abroad.
- The other 4 functions; Object, Scene, Selfie and Text Recogniser are all features of Seeing AI, the app developed by Microsoft for iOS devices. I think Seeing AI does a better job, with better descriptions, but if you're on Android and can't get Seeing AI, this is an adequate replacement.

ViaOpta Daily has seven languages built in: English, German, Spanish, French, Chinese, Arabic, Japanese.

ViaOpta Nav

The aim of this app is to allow a blind or vision impaired person to move independently thanks to the ability to walk to a destination starting from their position and have information useful to facilitate their orientation while moving. This information is provided and adapted taking into consideration the peculiar needs of a blind or vision impaired pedestrian and the app user interface is simple and easy to use.

The user can enter a destination and get the turn by turn directions from their current position to that destination. Way-points can be added to improve the effectiveness of the calculated route. While moving the app will also give information on next junctions as well as distances and directions.

At any time the user can query the app for their position and get it in terms of street address. The user can obtain a list of junctions around them, with the corresponding distances and bearings, can also be obtained.

Information relevant to user mobility, is provided by using the Text To Speech (even if no screen-reader is running).

In my brief testing of this app, I found it quite useful. I'd tend to use google maps by choice, but I like that this has a comprehensive list of what's around my location; junctions including distance and direction,, schools & libraries, ATM;s and banks, fast food and cafes. I understand Blind Square does a great job of this but its \$60 and this is free, so it might be enough for those who like the price point. I'd definitely suggest giving it a try. Who knows, you might discover a new coffee shop nearby!

ViaOpta Hello Preview

ViaOpta Hello has been designed as a personal assistant to help people with low vision identify the objects & people around them. You can use the app to:

- Understand the world around you with greater ease using features to identify objects and people.
- Register your friends and colleagues so that the app can call out their names when identified.

The app has been designed with large buttons and will integrate with your phone's accessibility functions such as 'Zoom' and 'VoiceOver' to ease its use.

Curiously I couldn't find it in the NZ App store but it is in Google store [android].

NZ Genetic Hotlines

Ring any of the following free-phone numbers if you want to speak to a genetic counsellor or geneticist about your own diagnosis of RP, macular degeneration or other retinal degenerative disorders.

Auckland Genetic Hotline
0800 476123 or 09 3074949
[ext 25870] [Northern Regional Genetic Service]

Wellington Genetic Hotline
0508 364 436 or 04 385 5310

Christchurch Genetic Hotline
0508 364 436 or 03 379 1898

RETINA NZ INC. VALUES, VISION and MISSION

Our Values:

Our work is underpinned by our values: Empathy, Respect and Ethical Practice.

Our Vision:

Equitable availability of safe and effective treatments for all people with degenerative retinal disorders.

Our Mission:

To support people in NZ experiencing sight loss, and their families & friends, by providing easy access to the information and support they might need at different stages of their sight loss journey.

VIP Support Groups

FEILDING: When: First Tuesday of the month, 4.00pm Where: Feilding Public Library. contact Jill 06 3236101 or Peter 06 3575020 or just turn up.

PALMERSTON NORTH: When: Third Tuesday of the month, 4.00pm Where: Palmerston North Public Library. contact Jill 06 3236101 or Peter 06 3575020 or just come along.

WAIKANAЕ: When: 1st Monday of the month Where: Cameo Rooms (Pop In Centre) on Mahara Place. Sue Patterson (04) 293 5174

KAPITI: When: 3rd Monday of the month Where: Paraparaumu Public Library, Elizabeth East (04) 299 1800

DUNEDIN: When: 4th Wednesday of the month, 1:30pm Where: Dunedin Public Library, 4th floor Dunnington Suite. Lynley Hood (03) 4877 686

We also hold public meetings around the country so give us a call to find out when we're next in your area. These groups are open to anyone with sight loss or their family & friends.

TAURANGA: Currently in recess. Enquiries contact Sue 0800 569 849

If you would like a group in your area contact Sue on 0800 569849 ext 2

DISCLAIMER & ACKNOWLEDGEMENTS

The opinions or position expressed in articles are the author's own views and do not necessarily express the policy or views of Retina NZ Inc. The products and services featured in Retina Newz are not tested by Retina N Z Inc.

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If you would like to receive an email version please email your request to secretary@retina.org.nz [so we have your correct email address].

If you would like to discuss your newsletter options, please phone **0800 569 849** [Ext 3]



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click the link to the [Retina Youth Page](https://www.facebook.com/Retina-Youth-142026759823048/) or go to <https://www.facebook.com/Retina-Youth-142026759823048/>

Click the link to the [Retina Youth Group](https://www.facebook.com/groups/104993146205839/?ref=group_header) or go to https://www.facebook.com/groups/104993146205839/?ref=group_header



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[Retina Youth - @retina_youth](#)

Our Publications ...

The NZ Low Vision Handbook is our 36 page A4 guide to coping with vision loss with all its daily challenges. It is also available in a range of accessible formats. You can get a FREE copy by contacting us on 0800 569849 or secretary@retina.org.nz

"Understanding ..." series Adapted from RNIB info for relevance in NZ. There are currently 4 booklets; RP, AMD, Cataracts and Retinal Detachment.

Other resources: We have Amsler Grids [A5 Card], business cards and the "Where do you turn" booklet [an overview of Retina NZ], which are useful handouts for eye professionals when talking to clients. Ask about our updated version of the "Good Look Book" - a compilation of stories by people living with sight loss and the unique experiences of their sight loss journey.

Retina Youth - "A Place For Us" is a DL sized colour brochure full of info and stories for young people by young people. It includes links to Facebook and Retina Youth website.



Where do you turn ... when you're losing your sight?

Our Publications



Peer Support



Support Groups



0800 569 849
(0800 LOW VIZ)

**Low Vision Support
and Information**

Retina NZ Inc.

