Hello everyone!

Welcome to your Winter edition of the newsletter, I hope you’re all keeping snug. This is a special issue as we are celebrating 25 years as an organisation! Kay McKenzie has put together an overview of Retina NZ’s origins for you to read, and we’re very grateful to her for taking the time. I hope you enjoy hearing about how it all began.

By the time you are receiving this newsletter I will be about to embark on a mission south. After eight years of being an Aucklander, I am returning to Christchurch, where I grew up. I am wondering how I will re-acclimatise to the weather, and I’m sure my cat is about to get a shock and grow some thicker fur. However, I am looking forward to being back in Christchurch, and will have to bring you a report once I’m settled on how the rebuild is going in terms of creating an accessible city for all (I have been keeping a distant eye on this for a while).

In these darker months it’s easier to spend more time watching TV or on the computer. If you have trouble with glare from your computer screen, then you might want to install a free programme called Flux. Flux will dim your computer screen with an increasingly apricot hue as the sun goes down, to prevent you staring at the harsh bright screen beyond daylight hours. It is very subtle, and I don’t find the change in colour affects contrast at all. I can’t use a computer without it being installed these days, and have even installed it on my phone. It helps with eye strain, and getting to sleep as normal as it eliminates the ‘blue’ light from your screen output. Go to www.justgetflux.com for more information.

In this issue I address two topics that I have received requests for information on; Charles Bonnet Syndrome and how to handle personal banking. In addition to this there are the details that you will need if you wish to utilise the new Telephone Dictation Voting service for the General Election next month. Please keep this newsletter somewhere safe, as it includes all the key dates, and the phone number, that you will need if you wish to register for Telephone Dictation Voting when registration for this service opens on August 21st.

I hope you enjoy the newsletter, and I look forward to seeing some of you at the AGM in Christchurch next month.

Till soon,

Zoe
editor@retina.org.nz
Dear members, friends and supporters,

Some of you may have heard the news already, possibly the most exciting news in our proud history of 25 years of achievement in peer support, public awareness and promoting treatment research. As a fitting recognition of 25 years of our society, Retina New Zealand and the University of Auckland won the right to host the Retina International World Congress in 2018!

Now this is truly exciting for us all. For three days in early February 2018, we hope to attract over 300 delegates to the world-class conference facilities within the Owen G Glenn building on the main campus of the University of Auckland. People with retinal disorders and their families, clinicians and researchers, blindness and disability sector professionals and organisations will have the opportunity to hear about the most promising of the latest research breakthroughs from the principal investigators themselves, meet patients from over 50 countries around the globe, hear from leaders in blindness rehabilitation and patient advocacy and gain an insight into the remarkable success story that is the Department of Ophthalmology at the University of Auckland.

International delegates will benefit from the department’s substantial expertise; the University of Auckland’s Department of Ophthalmology is one of the largest ophthalmic research institutions in the Southern Hemisphere. Retinal research is undertaken by a number of staff in the department, including Professor Colin Green, Associate Professor Philip Polkinghorne, Dr Andrea Vincent and Dr Ilva Rupenthal. The department has six clinical research fellows, two in surgical/vitro-retina and medical retina, who are undertaking a number of projects, including the current ‘Auckland Aflibercept in Wet AMD’ study.

Over the coming 3.5 years, I look forward to reporting on progress as we embark on an adventure in fundraising, programme development, and many other tasks. Along with the occasional dabbling in the murky worlds of diplomacy, language interpretation and crisis management I’m sure. Rest assured, however, we have already assembled a formidable line-up of volunteers in what could only be described as a dream team organising committee.

My gratitude to you all for being with us as we fly past the 25 year marker as a society – without your membership and confidence, much of what we will celebrate in this issue would not be possible.

Happy Spring

Fraser Alexander
President
The need is recognised

Back in the 1980’s there was a handful of people across New Zealand who recognised that a significant number of people with inherited eye diseases were being diagnosed, but due to not being ‘blind enough’ they had nowhere to turn for advice or help.

Among these were ophthalmologist, Dr Diane Sharp and some people with Retinitis Pigmentosa. Notable stirrers in this group were Maaka Tibble in Auckland, June Ombler in Dunedin and even earlier, Peter McGlinshy in Christchurch (1983). They independently set up support groups for their peers, which became the seeds of the NZRP Society. The North Island one was called the NZRP Person’s Society (they first met in 1988, and had their first AGM on 16th September 1989). The other surviving group was called the Otago/Southland RP Society (first public meeting in September 1989).

Both Maaka and June, along with John Manchester and Peter Simmonds, attended the 6th biennial International Retinitis Pigmentosa Association (IRPA) congress, held in Dublin in 1990. They came back knowing that if New Zealand was to become a full member, the two societies had to become one national society. The NZRP Society was quickly formed on their return, and achieved full member status of IRPA at the next congress in Johannesburg in 1992.

Forming New Zealand Retinitis Pigmentosa Incorporated

As with most processes to form an incorporated society, working towards a sustainable and legally acceptable constitution takes a long time. When the members of the organisation are scattered nationwide the process can seem interminable, but the committee and the members eventually got there, and it came into effect in January 1993. The new constitution was finally legally ratified on 26th November 1993.

Along with working towards a unified constitution, other things were necessary to become a member of IRPA. They needed to form a Scientific and Medical Advisory Board (known as a SMAB) to oversee any information that was to be passed on to members, ensuring its scientific viability. The SMAB could also recommend where research support may be needed within NZ. There has been a stellar line-up of scientists, ophthalmologists and optometrists connected to our society over the years, including Dr Dianne Sharp, Dr Michael Denton, Dr Marion Maw, Dr Gillian Clover, Gordon Sanderson, Dr Joanne Dixon, Dr Andrea Vincent, Dr Monica Acosta and many summer students who carried out the research.
Recognising the need for members to cooperate with the scientists to further the research, Dr Dianne Sharp obtained funding early on to set up and promote a national database of families with RP. NZRP Society also set aside its membership fees for supporting research, a practice that has continued to this day. In his final president’s report in March 1993, Maaka Tibble recognised the need for advice and support for members, which went on in an ad hoc way for several years. He also stressed the need for ongoing support of research towards a cure, the need to lobby for the establishment of multi-disciplinary low vision clinics, as well as making good connections with ophthalmologists and optometrists, so they could refer newly diagnosed patients to us for support.

- Growing into Retina NZ Inc.

Dan Phillips took up the reigns as the next president, and with the new constitution now in place, members elected two vice-presidents, one for the North Island and one for the South Island. This first constitution was written so that the term of a president was up to 4 years, and the vice-president from the other island would normally take over from them, ensuring not only fresh leadership but also an even bias for strategies and services within the society.

One of the aims early on was to form branches in all the main centres. Otago and Auckland already had groups, and Christchurch elected its first committee in September 1993.

Wellington came next in February 1996. Over time the branches have found it less cumbersome to close, instead becoming support groups, known as VIP (Visually Impaired Persons) groups, and there are now eight active groups meeting regularly throughout the country. The Kapiti VIPs celebrated their 10th anniversary in May 2014.

- Pamphlets and Peer Support

Some of the Executive had been answering telephone enquiries from distressed people and their families, newly diagnosed and without any information and support. It became obvious that well-researched information needed to be available. With the oversight of the SMAB’s scientists, various books were published, including “A Family Affair”, “About Macular Degeneration” as well as several pamphlets.

In addition, various people did a great deal of work to spread the word amongst the ophthalmologists, optometrists and the general public, sending out these publications and manning stalls at various expos around New Zealand. The Retina NZ website was launched on World Retina Day, 25th Sept 1999. But the most pressing need was a listening ear, and so the 12-strong, nationwide Telephone Peer Support Team was trained and commissioned in August 2000, with Elizabeth East as its coordinator.

For a lot of members, this will have been your first contact with Retina NZ, and we trust many have gained
renewed hope after a bleak diagnosis.

- **Widening our scope in line with Retina International**

Since our beginnings we’ve sent delegates, both members and scientists, to every biennial IRPA conference since 1990. This has meant we’ve been right up to date with the latest research and developments worldwide. It’s brought increasing hope that we and our children who’ve inherited retinal dystrophies may one day be able to regain some sight.

Research funding has always been critical, so IRPA worked towards widening its scope to include all retinal dystrophies, thus bringing in the much larger and better funded group with Macular Degeneration. Needing a name change, IRPA became known as Retina International. At the same time, the NZRP Society resolved to follow suit, and changed its name to Retina NZ Incorporated on 1st March 1999.

There have been so many unsung heroes in our society, and it’s impossible to name them all, but we are so grateful for their on-going legacy. However, we give special thanks to those providing our communications – the society’s secretaries: Sally Ferguson, Janet Palmer, Lyn Morgan and Sue Emirali, and also the newsletter editors: Sally Ferguson, Judy Lloyd, June Ombler, Susan Mellsopp, Camille Guy and Zoë Hill.

Some of the presidents have been mentioned already. Following June Ombler came Tony Haas, Kaye Newton and of course Fraser Alexander. Most recently, we welcomed the start of our very successful youth network in November 2011, headed up by Zane Bartlett, who edits the youth news, and now hosts the Retina Youth website and Facebook page.

This brief history has concentrated mostly on the early days, and much more could be written. Apologies are extended to those whose names and achievements have been left out.

One of our early pioneers, June Ombler, in her final president’s report in 1999, quoted Sara Henderson, saying:

“All the strength you need to achieve anything is within you. Don’t wait for a light to appear at the end of the tunnel. Stride down there … and light the bloody thing yourself.”

This attitude was certainly typical of her, but it’s also a challenge to us all not to give in to our disabilities, but to use every ability we have to change things for the better.
Wet AMD Trial

Call for participants

Have you just been diagnosed with wet AMD? Have you or someone you know experienced a change in vision in one or both of your eyes? Symptoms like a central blur or decreased intensity of colour and distortion may indicate macular degeneration (MD).

At Auckland Eye, Eye Institute or Southern Eye Specialists Ltd, we are researching to find the best treatments for wet MD so if you are diagnosed with this form you may be eligible to participate in our current study. If you have not had previous treatment for wet MD and qualify for this study, you will receive all the study medication, study related expert medical care at no cost and travel reimbursement.

Interested in learning more about the study and wet AMD? Contact the study clinics through the details below.

Auckland Eye:
Contact Name: May Mendoza
Email Address: research@aucklandeye.co.nz

Eye Institute:
Contact Name: Andrew Gerrie
Email Address: info@eyeinstitute.co.nz

Southern Eye Specialists Ltd:
Contact Name: Marie Taylor

Email Address: info@southerneye.co.nz

Please contact the centre nearest you to discuss the eligibility criteria and ask any questions.

Tech Bite: News Reading

By Zoë Hill

Vision impaired Australians have a new option on the market for staying up to speed with the news. A new product has recently been launched called RealSAM (Simple Accessible Media), by company RealThing (www.realsam.com.au).

It is essentially a smartphone with most other functionality locked down, it just accesses news and other media and reads it out to you.

Members of Vision Australia’s library can use the device to access Fairfax and Newscorp newspapers, as well as 300 regional newspapers, over 1000 podcast programs from ABC radio stations, BBC Radio, Canada’s CBC Radio and NPR Radio from the US, and the ever popular TED (Technology, Entertainment, Design) talks. It also understands several commands to help users find stories and navigate within stories, such as “start again”, “repeat”, or “jump forward five” or “jump back two”, which will move back or forth by that many sentences (or minutes if listening to a podcast). RealSAM links into the mobile phone network to access its data, and can also connect to WiFi. They are interested in expanding to NZ in the future.
By Zoë Hill

As we celebrate 25 years of Retina NZ, I thought it might be a good point to reflect on what have been the big milestones in terms of finding out about inherited retinal diseases during this time.

I asked a handful of our scientific minded colleagues here in New Zealand and some from overseas to answer the following question in one sentence only:

Q: “In your opinion, what has been the biggest advancement in the treatment of inherited retinal disease in the past 25 years?”

Dr Andrea Vincent: (Senior Lecturer, University of Auckland, Consultant Ophthalmologist at Greenlane Eye Clinic)

A: “The RPE65 gene therapy success first in an animal model, and then in humans, that has demonstrated the ability to “rescue” photoreceptors, restore functional vision to patients, and lead the way for many other gene therapy trials that are now in early phase clinical trials”

Dr David Worsley: (Consultant Ophthalmologist at Waikato Hospital, Ophthalmologist and retinal specialist at Hamilton Eye Clinic)

A: “The advances in our knowledge of the very building blocks of our cells and their inner workings. From this we now have a burgeoning knowledge of genetics and the first successful gene therapy for a retinal disease, and 'Biologics' - designer proteins such as Avastin which specifically target our knowledge of disease processes. Avastin and similar agents have reduced blindness from age-related macular degeneration by 30% in New Zealand.”

Dr Harry Bradshaw (Vitreo-retinal surgeon, Dunedin)

A: “The retina was the first ever tissue treated in humans to attempt to address genetic deficits leading to inherited blindness (Leiber Hereditary Optic Neuropathy) and is likely to expand dramatically over the next 25 years, although faces significant challenges.”

Prof. Michel Michaelides (Consultant and Clinical Senior Lecturer, Moorfields Eye Hospital, London)

A: “The huge progress made in establishing the underlying molecular genetic diagnosis and thereby enabling the development of gene replacement therapies”

Betty Ghent (President, Retina Australia - NSW)
A: “The move into clinical research using gene therapy.”

Dr Gordon Sanderson:
(Associate Professor, University of Otago)

A: “I think the recent advances in gene therapy hold the greatest promise for those people who have an inherited retinal disease.”

Dr Monica Acosta
(Senior Lecturer, University of Auckland)

A: “The use of biotechnology to develop retinal implants that has allowed shapes and movement perception to those otherwise totally blind.”

Dr Monika Pradhan
(Consultant Ophthalmologist at Manukau Superclinic, honorary Clinical Senior Lecturer, University of Auckland)

A: “The gene therapy trials are the biggest advancement in the treatment of inherited retinal disease in the past 25 years.”

A big thank you to everyone who took a moment from their busy days to participate.

AGM in Christchurch

By Zoë Hill

We would love you to come along to our AGM Meeting this year! Next month we will be meeting up in St Albans, Christchurch at the Blind Foundation rooms. We have some fantastic speakers lined up after the AGM formalities are over. Please feel free to bring family or friends along, all are welcome. For catering purposes RSVP by phoning 0800 569 849 (option 2 or 4) by 2/9/14.

The current president’s term ends in September 2014. At the AGM there will be an election of executive committee members for the term 2014 – 2015. Nomination forms can be completed up to just before the AGM. The nominator, seconder, and the persons standing all must be current financial members of Retina NZ. If you wish to nominate someone, or require a proxy form, could you please phone our peer support line (0800 233 833) or email membership@retina.org.nz and you will be sent the relevant forms.

Retina New Zealand
Public Meeting and AGM in Christchurch on Sat 6th September
Where
Blind Foundation Rooms
96 Bristol St
St Albans, Christchurch

Guest Speakers:
Dr Jim Borthwick & Logan McMullan

Time
AGM-10.30am
Lunch-12.00pm
Public Meeting-1.00pm

Any members of the public who have a sight loss issue are welcome to attend.

0800 569 849 or (03) 338 1559

RSVP by 2/9/14 for catering purposes
In March the Vice President of the Canadian Institute for the Blind (CNIB), Dr Keith Gordon, visited our Auckland Retina NZ branch meeting. He spoke on a variety of topics, but I have included a short write up on what he presented on the topic of Charles Bonnet syndrome, as I have received some requests for information on this topic.

Dr Gordon reported on a study conducted by CNIB in collaboration with the New Zealand Blind Foundation on the prevalence of Charles Bonnet Syndrome in clients attending vision rehabilitation at these two organisations.

Charles Bonnet Syndrome (CBS) is defined as: ”the experience of complex visual hallucinations in people with vision loss”. It is named after Charles Bonnet who first reported the condition. Charles Bonnet (1720 – 1793) was a Swiss naturalist, a lawyer by profession who wrote about the condition he observed being experienced by his grandfather. Bonnet’s grandfather had gone blind due to cataracts and was observing men, women, carriages, buildings, tapestries and scaffolding patterns that weren’t there. Bonnet knew that his grandfather was mentally sound and that the hallucinations were not the product of a mental disorder.

Much more recently, in a study published in 1995, the following criteria were established to distinguish between Charles Bonnet hallucinations and other forms of hallucination:

- Charles Bonnet hallucinations are complex, repetitive and persistent
- The person perceiving these hallucinations knows that they are not real
- The person has no additional delusions
- The hallucinations are present in the absence of additional delusions in other senses

The current study was undertaken, since there were very few studies on the prevalence of CBS in which all of the major eye diseases were studied in the same study. There were no known studies on prevalence of CBS in people undergoing vision rehabilitation, and there was great reluctance of vision professionals to discuss this condition with people with CBS, coupled with a reluctance of people to speak with their eye professionals about their condition for fear that they might be perceived as mentally ill.

During the months of July to December 2013 CNIB and the NZ Blind Foundation asked the following question of all clients undergoing an initial needs assessment at each organisation:

“Many people who come to CNIB/the Blind Foundation tell us that they see things they know are not there. Some see patterns or shapes. Others see images of people or animals.
Have you ever experienced this?”

This question had been used in a previous study conducted at Harvard University on people with glaucoma. We thought it would be a good opportunity for a direct comparison.

CNIB were able to obtain a sample of 2,565 new clients undergoing vision rehabilitation over this period and the NZ Blind Foundation had a sample of 290 clients over a slightly shorter period of time. The samples were essentially the same with respect to gender and age composition, however the New Zealand sample had a greater degree of vision loss.

The results showed that 18.8% of people undergoing vision rehabilitation at CNIB had experienced hallucinations, while 30% of the NZ Blind Foundation sample had experienced hallucinations. The difference between the CNIB and the NZ Blind Foundation prevalence can be explained on the basis of the NZ Blind Foundation members having a greater degree of vision loss.

The results of the study, in fact, showed that more people with a greater level of vision loss experienced hallucinations. Another significant finding of the study was that there was no significant difference between the prevalence of hallucinations in people having Macular Degeneration, Glaucoma or Diabetic Retinopathy. The prevalence of the hallucinations appears to be due solely to their vision loss, not the cause of their vision loss.

One in five to one in three people coming to Vision Rehabilitation Organisations are experiencing hallucinations. It is important that Vision Rehabilitation staff know how to initiate the discussion with these people. Most people just want to know that there is not another cause. It is also important that people with hallucinations are referred to medical specialists in order to make sure that these hallucinations do not have another medical cause.

This study showed that people with greater vision loss had a higher risk of having hallucinations than people with lower levels of vision loss, and the risk of having hallucinations was not significantly different for the three major eye diseases.

By Zoë Hill

If you are thinking of starting out with JAWS, or brushing up on your use of it, then you might want to consider their new training bundle, which includes enhanced training options. New Zealand JAWS provider Pacific Vision are stocking the training bundle from August 1st, and will be pricing it at $1071.45 + GST. It has 51 hours of training included, and eight optional progress exams, which works out at roughly $24 an hour for tuition.

Freedom Scientific also have free webinars archived and accessible here: www.freedomscientific.com
Science Update: Retinal Implants

By Zoë Hill

In a report published last year by the Centre for Ophthalmology at the University of Tübingen in Germany, an overview was given of the current state of electronic visual implants for those with RP. Two electronic implants are now registered medical devices; Alpha IMS and the Argus II.

With Retinitis Pigmentosa, the rods and cones die. As a result, the retina’s inner cells and the optic nerve fibres that normally send impulses to the brain stop receiving information. Retinal implants try and work directly in this area with what is left, to re-establish communication. Implants are most commonly categorised by where they work; either epiretinal (fibrocellular tissue found on the inner surface of the retina), or subretinal (behind the retina).

Alpha IMS (subretinal)

Subretinal implants are placed in the natural localisation of the photoreceptors, under the retina in the centre spot (macula). According to Retina Implant AG’s website, “the macular region is believed to be the ideal location because this is where light-sensitive photoreceptor cells are located which are responsible for producing clear images in normal-sighted people.” The subretinal implant chip’s 1,500 light sensors are triggered by natural light. Electrical impulses stimulate the retina’s inner neurons and signals are sent to the brain to produce sight. The chip is powered by a small battery box which provides power and controls for brightness and contrast adjustment. Communication is via a wireless unit behind the ear to the implant by a sub-dermal coil and cable that runs to the eye.

According to the report, one of the main advantages of subretinal implants is the “relatively natural feeling of perception” due to the fact that the remaining visual pathway is used and the information processing in the inner retina can be utilised. Although the image is perceived in shades of grey, the report also states that the “number of pixels creating the electronic image in subretinal implants is the highest of all visual implant devices developed so far. This allows for a higher resolution of vision and more potential for the functionality of vision”. Also, the chip also moves with the eye, which means you don’t have to move your head to recognise objects as with the epiretinal implant.

Argus II (epiretinal)

A miniature video camera is located in the patient’s glasses. Video is sent to a small patient-worn computer and transformed into instructions that are sent back to the glasses via a cable. These instructions are transmitted wirelessly to the implant. The signals are then sent to the electrode array, which emits small pulses of electricity. These pulses
are intended to bypass the damaged photoreceptors and stimulate the retina’s remaining cells, which transmit the visual information along the optic nerve to the brain.

A huge part of implant development is making them from components that are stable and able to be accepted by the eye in the long term. The report states that in clinical and pilot trials of the Alpha IMS “most patients considered the regained visual functions in their daily lives useful, reporting recognition of facial and clothes characteristics, detection and identification of items at their homes or offices, seeing street or car lights at night or finding objects in unknown environments.”

The new Telephone Dictation service has been developed with testing and input from the Blind Foundation and Blind Citizens New Zealand. However, this does not mean that you have to be a member of the Blind Foundation to access the services.

As the Electoral Commission’s Communications and Education Advisor, Richard Thornton, states “the registration process won’t seek medical records or any form of testing. Voters will be required to make a declaration that they cannot mark their ballot paper without assistance because of disability. The purpose of the new service is to provide an option for people to cast a secret vote who otherwise would not be able to.”

To utilise this service you MUST register. This means you have to ensure you are 1) enrolled to vote AND 2) registered to vote by phone.

Call 0800 028 028 to register

Registration opens:
Thursday 21st August
Mon - Fri (9am - 5pm, changing to 9am till 7pm from 15th September)

Registration closes:
Thursday 18th September 7pm

Dictation Voting opens:
Wednesday 3rd September
Mon - Fri (9am - 5pm, changing to 9am till 7pm from 15th September)

To watch a video on the service: http://youtu.be/XIljkDrjH9Y
I had an enquiry from a member since the last edition of the newsletter about how to cope withdrawing cash, and whether some ATMs are better than others.

I asked our major banks in New Zealand about what they are doing to make sure their ATMs are accessible, and I received answers from all of the banks I approached. Blind Citizens NZ has done a lot of work in this area to ensure that talking ATMs are part of normal banking routines here in NZ.

For those who might be hesitant to use ATMs on the street, remember there are a lot of ATMS within the larger shopping malls these days, where having more people around and mall security might make you feel more at ease.

**Banking standards in NZ**

The issue of accessibility of banking services is covered by the New Zealand Banker’s Association (NZBA) Voluntary Guidelines to Assist Banks to Meet the Needs of Older and Disabled Customers, which is incorporated by reference into the Code of Banking Practice.

The Voluntary Guidelines encourage banks in adopting the guidelines to have regard to the latest ATM technology and how that can be used to benefit the elderly and those with disabilities. In addition, NZBA hosts an annual working group of member banks and representatives of community organisations to address accessibility concerns and the functioning of the Voluntary Guidelines.

- **How the audio-enabled ATMs work**

First of all you will need some headphones. Often, cell phones come with a set of headphones, or they can be bought for about $14. Talking ATMs have a standard sized headphone jack (3.5 mm jack plug), however placement of the jack may vary from machine to machine. Once you have plugged them in, the ATM will guide you through the basic transaction processes using the keyboard. As per standard guidelines for disability access, all keyboards have a raised dot on the #5 key to provide context for the other keys.

To use the ATM, insert headphones into the jack and the tutorial on how to use the ATM starts. At any stage you can exit the tutorial and start the transaction by inserting a card. The audio service is scripted to guide you through the main services. During an audio assisted transaction the ATM displays a screen highlighting that an audio transaction is underway, rather than displaying the normal transactional screens to keep your information private.
How well does your bank look after you?

Westpac

For some years now, Westpac ATMs have been audio-enabled “smart ATMs”. This was completed on 2010, so now 100% of Westpac’s 120 ATMs have this functionality. The ATM is not able to guide the user through the deposit process, however, all other transactions, for example withdrawals and balance enquiries, are able to be performed.

Kiwibank

Similarly, Kiwibank ATMs have a headphone jack to the left of the keypad on each ATM.

ANZ

Currently, 90% of their 680 ATMs have audio capability. ANZ plan to replace or upgrade all ATMs by the end of 2015 which will include audio assistance as a standard going forward to provide audio access to people with impaired vision.

ASB Bank

90% of the ATMs in the ASB network are audio-enabled, and every new ATM purchased is audio-enabled, so they are aiming for 100%. Also, ASB’s internet banking is tested to work with popular screen readers, including testing with visually-impaired members of staff.

TSB

TSB operates only a small number of ATM's, most of which are situated in the branch or just outside the branch. TSB mentioned that while they don’t have talking ATMs, the positioning of their ATMs allows for low vision customers to instead be supported by the Branch team.

The Co-operative Bank

The Co-operative Bank only has 34 branches do not have their own ATMs. However they have done work on their internet banking to ensure it is accessible for as many people as possible.

Other money handling tips

There are options for using certain cards with no need to enter a pin or to sign.

According to Visa’s NZ website, their ‘payWave’ method of paying via credit card is accepted at retailers such as BP, Z Energy, The Warehouse, Bunnings, Farmers, Glassons, Event Cinemas and a growing number of quick service merchants including SUBWAY and Burger King. Visa states that their payWave-enabled cards are as secure as their chip cards, and carry the same multiple layers of security, which ensures that users are not responsible for fraudulent or unauthorised transactions. The limit for a payWave transaction is $80.

Visa payWave cards only work when the card is within 4cm of the card reader and the payWave terminal can only process one transaction at a time. Because the Visa payWave card doesn't leave your hand during
the transaction, you remain in control of your card at all times.

Mastercard also have the same functionality called PayPass. They do not list the participating retailers on their website. If you have a Mastercard or Visa card, it may already have this functionality built in. Contact your bank for more information.

- **Keeping your money together**

Handling coins can be easier than notes. The new 10, 20 and 50 cent coins were introduced 8 years ago now. The 10 and 50 cent coins have plain edges, while the "Spanish flower" edging on the 20 cent coin makes them easier to tell apart. Notes, however, are a different story. Keeping notes of the same denomination together, and in different sections of your wallet will help in keeping track of things.

The Blind Foundation sells notegauges ($6 for both members and non-members), which are available in pocket size and regular size. They measure New Zealand $5, $10, $20, $50 and $100 notes. It is a single piece of solid white plastic in which notes are slotted for measuring. Denominations are marked in Braille.

Last month it was announced that NZ's bank notes will be getting a facelift. All notes will be updated to match current security measures (from $5 to $100) but the size and material won't change. They will also have larger fonts stating note denominations and a bigger difference in colour between notes. The upgraded notes will be in circulation by the end of next year.

**Darkest Before Dawn**

By Gyles Baskett

After an accident I was partially sighted for 16 years. I had repeated surgery. In the final years I could only read by using a screen enlarger and even then I struggled to read print. Some days the fluid within the eye ball seemed to be full of a nebulous haze which limited details even more.

I took cortisone tablets, eye drops. I was teaching English at the time and sometimes I could barely see the students. I did not use a white cane because I considered myself as part of the sighted world, struggling a bit, yes, but getting around streets and the centre of town okay. When I look back on those years, the difficulty was the instability of life. The doctor visits, the tedium of waiting rooms, the unpredictable changes in my vision, the stress of reading and shopping, of constantly peering at little diagrams, at microwave buttons, at keyboards, at labels.

Then suddenly, one eye gave up and in a month or two the other eye collapsed. I was 39. I remember feeling shattered for about 3 days. Then I realised the stress of living in a dual world with one foot in the sighted world, one in the mists of low or no vision, was over.
My blindness was final. It meant stability. It meant that the perimeters of my daily life were clearly defined. I had no other choice but to get on with things, and to my surprise I felt relief. I was no longer trying to straddle both worlds. I was now in the world of the blind and there was no way out!

With my role so clearly defined I had to get on with learning as many new skills as I could. At that time the Blind Foundation had a residential unit in Maunselle Road, Auckland. I was invited to stay at no cost for a fortnight to gain new skills. There were New Zealanders from all over the country. We learned how to use a cane, a lot of helpful daily skills and we had companionship with others recently blind. This was a tremendous help. I cannot emphasize enough the need for people to receive help.

I was lucky. Rather than brooding, isolated and frustrated at home, the skills I learned gave me confidence and independence. I urge anyone recently blind to seek out as much advice as is available from trained staff.

Then there were the positive elements of being blind to be discovered. Being blind allows us to simplify our lives. In a complex world this is a blessing. Out there are a huge number of things that can still give us pleasure. Not only are there many different blind groups, but other groups in the wider community. There are many like Toast Masters, garden groups, historical societies, motorbike enthusiast groups... whatever you are interested in - do not talk yourself out of participating. Obviously you’re not going to feature as a star on the tennis court, but you may well be amazed at how welcoming people are. Those who are passionate about their sport or hobby are usually very genuine in their desire to make you feel included. We alone can discover our limits; no one else can prejudge them. Chase your dreams.

Free AMD Seminars

By Zoë Hill

As we mentioned in our last newsletter, Macular Degeneration NZ are holding free education and treatment seminars on AMD. These are already underway and moving around the country, still to go are:

Dunedin: 16th August
New Plymouth: 23rd August
Gisborne: 13th September
Tauranga: 4th October
Napier: 1st November
Auckland: 15th November

Phone 0800 622 852 or email info@mdnz.org.nz to register attendance and confirm venue as capacity is limited.
Retina NZ has support groups in various locations around the country. These groups are open to anyone with any degree of sight loss or their family and friends.

Most of our groups meet monthly, and the people who attend find the advice, companionship and practical support very valuable. If you would like to explore the possibility of starting a group in your area, please contact Sue on 0800 569 849 (ext 2).

KAPITI:
When: 3rd Monday of the month
Where: Kapiti Community Centre

In July, 31 members heard an interesting presentation about Audio Books given by staff from the Blind Foundation. Information was given about the different formats of audio books and the different devices that can be used to listen to them. These ranged from dedicated e-readers (eg: Kindle and Kobo) to tablets and iPads, and a variety of phones as well as specific reading devices (eg: Victor Reader and Plextalk Pocket). It was pointed out that the Kindle e-reader is not compatible with the public libraries’ Overdrive system, and only permits downloads from Amazon, so these have to be bought. The public libraries’ Overdrive system permits free download of audio and e-book material for a fortnight.

Elizabeth East (04) 299 1800

TAURANGA:
When: 1st Saturday of the month, 10.30 till 12pm
Where: Tauranga Library
Sara Ash (07) 570 0917

OTAKI:
When: Monday 2nd December, 1pm
Where: Citizen’s Advice Rooms, Main Street, Otaki
Sue Emerali - 0800 569 849 (ext 2)

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

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

HAMILTON:
Mike Smith - 0800 569 849 (ext 3)

AUCKLAND:
Fraser Alexander - 0800 569 849 (ext 1, evenings only)

NEWLANDS:
Gael Hambrook - (04) 970 3575

CHRISTCHURCH:
Petronella Spicer - 0800 569 849 (ext 4)
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What format of newsletter would you like?
(Member may receive an email version in addition to either a print or CD copy at no extra cost)

Email:
If you would like to receive an email version please email your request to membership@retina.org.nz so that we can ensure we have the correct email address.

CD or Print:
If you would prefer to receive it as an audio CD or in large print please phone 0800 LOW VIZ (0800 569 849 Ext 2 or 4).

Publications:
A range of helpful brochures and books are available free of charge to our members. Please contact us via secretary@retina.org.nz or by phoning 0800 LOW VIZ (0800 569 849 Ext 2). Bulk orders are available to eye care professionals on request, however there may be a small charge to cover postage to non members and businesses.

Mission Statement:
To promote public awareness of retinal degenerative disorders; to provide information and support; and to foster research leading to treatment and an eventual cure.

Retina New Zealand Inc is grateful to the Blind Foundation, and the New Zealand Lottery Grants Board for helping to fund this newsletter.
Do You Need Help or Advice?
The Retina NZ Peer Support programme is a free and confidential service operating nationwide. To make contact with one of Retina New Zealand’s peer supporters telephone 0800 233 833. All calls are treated in strictest confidence.

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

**Auckland Genetic Hotline (Northern Regional Genetic Service)**
0800 476 123 or 09 307 4949 ext 25870

**Wellington Genetic Hotline**
0508 364 436 or 04 385 5310

**Christchurch Genetic Hotline**
0508 364 436 or 03 379 1898

PO Box 2232 Raumati Beach, Paraparaumu 5255