*CANBERRA BLIND SOCIETY (CBS)*

*July 2019 Newsletter* 408

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| **Southern Cross Club Community Rewards Program**  Members of the Southern Cross Club can help us raise funds by taking part in the Southern Cross Club’s Community Rewards program. Nominate the Canberra Blind Society as your organisation to benefit under the rewards program and ten percent of your purchases made on food and beverages in the public restaurants, bars and grills are included. |

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# Notice Board

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| **July 2019** | | | | |
| 3 July | First Wednesday | 10:00 | | Audio Book Club |
| 4 July  11 July  18 July  25 July | Thursdays | 9:30 | Braille Group | |
| 19 July | Third Friday | 10:00 | | Sense-Able Cooking |
| 23 July | Tuesday | 12:30 | | Christmas in July |
| **August 2019** | | | | |
| 7 August | First Wednesday | 10:00 | | Audio Book Club |
| 8 August  15 August  22 August  29 August | Thursdays | 9:30 | Braille Group | |
| 16 August | Third Friday | 10:00 | Sense-Able Cooking | |
| **September 2019** | | | | |
| 4 September | First Wednesday | 10:00 | | Audio Book Club |
| 5 September  12 September  19 September  26 September | Thursdays | 9:30 | Braille Group | |
| 20 September | Friday | 10:00 | | Overview |
| 27 September | Fourth Friday (this month only) | 10:00 | | Sense-Able Cooking |

# From the President’s Chair – Peter Granleese

Welcome once again to the July issue of the CBS Newsletter and the half way mark for 2019. In previous issues, I mentioned that CBS successfully applied for funding under the National Disability Insurance Schemes (NDIS) 2018/19 Information, Capacity and Linkages (ILC) funding round.

The grant will enable CBS to appoint a Project Manager for 12 months, to develop strategies increasing the Society’s organisational capacity by encouraging blind or vision impaired individuals to assist in the running of CBS. We are particularly interested in those vision impaired individuals with lived life experiences managing the effects of blindness in a range of capacities who are able to pass on those experiences in various roles, such as administration and management, peer support, advocacy or facilitators of services CBS may provide.

Since the loss of ongoing Government funding in 2017 and the departure of RSB in the same year, CBS has continued with the assistance of a small number of vision impaired volunteers who undertake the day to day running of the Society and provide a limited number of services and social activities. For example, weekly Braille and monthly cooking classes, monthly book club, social lunches and publication of the Monthly Newsletter, are all facilitated by vision impaired volunteers with some assistance from their sighted friends. Increased organisational capacity will enable CBS to have the necessary resources to increase services and train sufficient volunteers to insure its viability on into the future.

Prior to the introduction of the NDIS, CBS was able to provide a comprehensive outreach program that addressed most of the needs of our community. Quite often close relationships developed between CBS staff and clients, leading to lifelong friendships. As a consequence, CBS had a greater insight into the needs of the 300 clients on the books in 2014 when the NDIS commenced operation in the ACT.

A large number of these clients are now covered by the NDIS and receive funding to purchase services from a provider of their choice. Quite often, this means purchasing services from multiple providers. Now that these people go directly to their service provider, our window into the needs of the vision impaired community is not what it used to be.

The first task of the Project Manager will be to develop strategies to reconnect with the vision impaired community in the NDIS era and identify those services not covered by the Scheme. That there are gaps in services, has been recognised by the NDIS through the provision of ILC funding, designed to assist small DPOs like CBS, who still continue to play an important role delivering services in the disability sector.

Without pre-empting what those strategies might be, we can say that focus groups will play an important role in determining the kind of services CBS should be providing.

Once the level of service has been determined, the Project Manager will develop and implement training programs designed to train volunteers to deliver the programs.

The Project Managers position has been advertised and we hope the position will be filled by the end of July. Watch this space.

# Interlinked: A tactile exhibition of environmental jewellery and sculpture.

27th June to 21st July Strathnairn Arts, 90 Stockdill Drive Holt

‘Interlinked’ is the first solo exhibition by environmental and inclusive artist Ceilidh Dalton. The exhibition will be a series of tactile sculptures and jewellery designed to enhance appreciation for local biodiversity and engage the community in conservation.  The official opening was on Sunday, 30th June. Exhibition is wheelchair accessible, audio described and braille translated.

Artist talk and demonstration is scheduled for 11am Sunday, 14th July 2019 and is suitable for vision-impaired attendees with a guided audio description tour. An Audio description podcast is available from:

<https://anchor.fm/ceilidh-dalton/episodes/Art-in-words-Interlinked-e4fr76>

Please contact the artist directly for your access needs on [0411210949](tel:0411210949) or email [ceilidhdaltonmetalartist@gmail.com](mailto:ceilidhdaltonmetalartist@gmail.com)

# Hearing tests - Australian Hearing

The Australian Hearing Group has offered to come to CBS and conduct short hearing tests. They will be held at the CBS offices on Tuesday July 23 following the Christmas in July lunch. Each appointment will be about 15 minutes long and will give you an opportunity to get feedback on your hearing and ask any questions you may have. Appointments will be available from 2:30 until 4. Please email the CBS office at [canblind@canberrablindsociety.org.au](mailto:canblind@canberrablindsociety.org.au) if you are interested in an appointment.

# JAWS/Zoomtext group training

A small number of blind and vision impaired people who are employed are seeking to have a group training session with Pacific Vision here in Canberra for the screen reader JAWS and the screen magnifier Zoomtext.

To ensure the trip is worthwhile and costs can be minimised, I am seeking interest from members of the Society who would like to join this training. At this point, we are yet to confirm a venue or devices etc. and will confirm this if interest is shown.

Please email me at [scott.grimley@gmail.com](mailto:scott.grimley@gmail.com) as soon as possible if you are interested in group training sessions for JAWS and Zoomtext.

# What’s on at CBS

**Canberra Blind Society merchandise**

The Canberra Blind Society is selling merchandise with our name and logo. There are Notebooks ($20) with a debossed image of our logo and name on the cover, Keep Cups (for your coffee) ($15) with our name and logo on the silicon ring, Pens ($5) and Sunglasses ($10). The sunglasses offer UV protection for your eyes. Everything is available at our office in the Griffin Centre.

**Christmas in July**

The annual Christmas in July lunch will be on Tuesday 23 July commencing at 12 in room 6 Level 1. Cost as usual will be $10. Just a reminder that we need to have 30 attendees to cover our costs so we would appreciate an early indication of those attending for catering purposes. Contact the office on 6247 4580 or send us an email [canblind@canberrablilndsociety.org.au](mailto:canblind@canberrablilndsociety.org.au) if you would like to attend. Note if the office is unattended when you call please leave a message on the answering machine.

# The Way I see It – Graham Downie

Many years before computers and associated technology gave blind people access to printed material, the now, almost forgotten Optacon, allowed blind people to bridge that gap.

I was still at school when I first learned of the early stages of the development of the Optacon. During the 1970s I learned how to use it and it remains important for many tricky tasks for which no computer or app is available.

The reason for mentioning it is not to promote its use, because the product has not been produced for more than 20 years and the likelihood of obtaining one is remote. But I would like to stimulate interest in a product with similar capabilities.

As a tool for reading printed material, the Optacon cannot compete for speed with modern scanners and optical character recognition software. But as a device for identifying exactly where on a page particular text is placed, the Optacon is the only available technology for blind people without assistance.

I was again reminded recently of the importance of this largely forgotten piece of equipment when sent a document requiring my signature. Using the Optacon, I identified the spot on the page where I should sign. Having signed, I could even check that my pen had worked and that the signature was, near enough, in the correct position.

If you have read this far, you will probably want to understand how the Optacon works. First, some history of its development.

In 1962, during a sabbatical year in Switzerland, John Linvill, a professor of electrical engineering at Stanford University, visited an IBM laboratory in Germany, where he observed a high speed printer which used small pins to print letters onto strips of paper.

He thought, "If you could feel the hammers with your fingertip, you could surely recognize the image.”

On his return to Zurich, he told his wife, son and blind daughter Candy, he had an idea which would let her read printed material.

Despite his family’s scepticism, back at Stanford, Linvill, together with graduate students GJ Alonzo and John Hill, developed the concept further with the support of the Office of Naval Research. A key aspect of Linvill's concept was to have vibrating pins in a two-dimensional array to produce tactile images of printed letters.

A small camera, attached to the main unit by cable, is passed over the printed page, allowing the blind reader to feel each letter. It must be understood, this is not an easy task, though some people have read at 100 words a minute. Not this user.

First, with cold hands, I cannot use the Optacon at all. Further, there is only so much one’s index finger can tolerate when subject to the vibrating pins. Nevertheless, it remains an important tool on my desk; to confirm a cheque is correctly set out; to check a page number is where I wanted it; and occasionally to interpret print beyond the scope of OCR software. Using a different camera, some people have used the Optacon to interpret the layout of a computer screen.

But the product is now on the seriously endangered list. There are perhaps only four people in Australia and a couple in New Zealand who still use it. Though some dedicated users, particularly in the US, harbour hope that this or a product with similar capability will be developed, commercial reality suggests this is unlikely.

# New Orientation and Mobility specialists at Guide Dogs ACT

There are two new staff members at Guide Dogs – Karen Drew and Alan Jones. They are O&M specialists doing their practicum at Guide Dogs ACT and are available for consultation – contact the office to book an appointment (6285 2988). They will be visiting CBS on Tuesday 23 July and hope to meet CBS members at the Christmas in July lunch.

# Articles for the Blind postal concessions have been updated

Australia Post delivers domestic mail to the vision-impaired free of charge. Large print material now goes post free and the weight of parcels that are post free has been increased to 22kg.

**Special delivery for the vision-impaired**

Sending a parcel or letter that helps the blind? In most cases, you can send it for free. For domestic letters, eligible items must weigh no more than 500g, and domestic parcels must be under 22kg.

**Check what items are eligible on the list below.**

Eligible items

* Correspondence, documents or literature written in completely in embossed characters as used by the blind, such as Braille or Moon
* Aids for the teaching of Braille
* Plates for embossing literature for the blind
* Special paper intended solely for the blind, on the condition that any communication on the paper is wholly in Braille or Moon
* Any form of speech recording for use by the blind
* Large print products

In addition, the sender and or the recipient must be a blind person, or the sender and or the recipient must be an organisation Australia Post recognises as serving the needs of blind people

**Send your items in 3 easy steps**

1. Check the eligibility criteria of your article
2. Make sure the delivery or return address is written on the outside of your article
3. Attach an 'Articles for the Blind' label (available at Post Offices) or write the words 'Materials for Use of the Blind' on your article.

# Audio Description at Canberra Theatre

**Shakespeare in Love**

Audio described Saturday 31 August 1.30pm – Tactile tour 12.30pm

Canberra Theatre, Canberra Theatre Centre, Civic Square, London Circuit, Canberra City

Box Office 6275-2700

Companion Cards accepted - please mention Audio Description when booking

Presented by: Canberra Theatre Centre presents a Melbourne Theatre Company production.

Based on the screenplay by Marc Norman & Tom Stoppard. Adapted for the stage by Lee Hall.

Music by Paddy Cunneen

Director: Simon Phillips

Cast includes: Aljin Abella, Laurence Boxhall and Adam Murphy

Duration: 180 minutes including interval

Content warnings: This show contains some simulated fighting, sexual references, occasional coarse language and may contain strobe lighting and fog/haze effects.

A DELIGHTFULLY CLEVER ROMCOM THAT BRINGS THE OSCAR-WINNING FILM TO STAGE.

Young Will Shakespeare has a bad case of writer’s block and desperately needs a muse. His new comedy, Romeo and Ethel the Pirate’s Daughter, is less than inspired and he’s running out of time to deliver his next masterpiece. That is, until he meets Viola, and a real-life Romeo and Juliet story starts to take hold. But Viola has a secret, and this damned Romeo play is turning out to be nothing like the comedy the Queen demanded.

Shakespeare in Love won seven Oscars in 1998 when Gwyneth Paltrow and Joseph Fiennes stole our hearts on screen. Now, Tom Stoppard and Marc Norman’s Academy Award-winning script has been transformed by Lee Hall (Billy Elliot) into a side-splitting stage comedy with a stirring love story at its heart. With acclaimed director Simon Phillips (Muriel’s Wedding the Musical) at the helm, this unique theatrical event guarantees a rollicking night of romance, backstage fun and lavish musical accompaniment.

**Much Ado about Nothing**

Audio described Saturday 19 October 2pm – Tactile Tour 1pm

The Playhouse, Canberra Theatre Centre, Civic Square, London Circuit, Canberra City

Box Office 6275-2700

Companion Cards accepted - please mention Audio Description when booking

Presented by: Bell Shakespeare

Playwright: William Shakespeare

Director: James Evans

Cast includes: Zindzi Okenyo

Duration: Approximately 160 minutes including interval

CLAUDIO AND HERO ARE DEEPLY IN LOVE. BEATRICE AND BENEDICK WOULD RATHER SWAP SASSY INSULTS THAN SWEET NOTHINGS.

Much Ado About Nothing is a saucy and razor-sharp battle of wits between the bickering Beatrice and Benedick, who wield words as weapons, their banter betraying their love for each other. Claudio however is quickly consumed by envy and his idyllic world threatens to come tumbling down as he humiliates Hero. Beatrice and Benedick must join forces to defend true love – even if they can’t recognise it in themselves. But will truth and honesty win the day, and does love really conquer all?

Directed by Bell Shakespeare’s Associate Director, James Evans (Julius Caesar) and starring Zindzi Okenyo (Antony and Cleopatra, MTC’s An Ideal Husband) as Beatrice, this Much Ado About Nothing will be a powerful exploration of the struggle for identity and self-knowledge in a male-dominated world. The pursuit of love is framed in a social context that enhances the darker themes in this timeless comic gem.

Much Ado About Nothing is one of Shakespeare’s contemporary comedies where romance is thwarted by dastardly plots, misinformation, false accusations, broken promises, and bumbling cops. Or is it?

**West Side Story**

Audio described Sunday 20th October 1pm

Canberra Theatre Centre, Civic Square, London Circuit, Canberra City

Box Office 6275-2700

Companion Cards accepted - please mention Audio Description when booking

Director and Choreographer: Joey McNeely

Content warning: Please note this production contains strong language and adult themes; not recommended for children under the age of 12

Love, loyalty, and fate. The moment the curtain went up on the original West Side Story on Broadway, musical theatre changed forever. Hailed as the greatest Broadway musical of all time, the genius of West Side Story's creators is unquestioned. The remarkable collaboration between Leonard Bernstein, Arthur Laurents, Stephen Sondheim and Jerome Robbins produced a timeless masterpiece. Bernstein’s world-famous score features unforgettable songs including ‘Maria’, ‘Tonight’, ‘Somewhere’, ‘America’ and ‘I Feel Pretty’, that have been universally adored for generations; proving this iconic dance musical remains one of the most poignant stage works of the twentieth century.

A modern retelling of Romeo and Juliet; this tragic love story tells the tale of two young people whose happiness is destroyed by the hate of two enemy camps in New York City’s urban jungle. The Jets, sons of previous immigrants to America, battle the new arrivals from Puerto Rico, the Sharks, for domination of the streets.

Director Joey McKneely’s vibrant new staging will feature some of Australia’s most exciting young talent performing Jerome Robbins’ original ground-breaking choreography in two of Australia’s most iconic theatres. The ideal fusion of dance, music, and theatre; experience this internationally celebrated production of West Side Story for a limited season only.

# Medical News

## Alzheimer's eye test to enter trial phase in hopes of diagnosing before symptoms appear

Melbourne researchers have developed a non-invasive, cost-effective eye test to detect early signs of Alzheimer's disease.

The Centre for Eye Research Australia (CERA) will fast-track its research and begin clinical trials in August, after a $600,000 donation from a group of American philanthropists including Bill Gates and MacKenzie Bezos.

The world-first eye scan trial will use technology like that used in NASA satellites, [to look for abnormal proteins that build up in the brain through the retina](https://www.abc.net.au/news/2016-11-11/alzheimers-disease-eye-test-could-predict-development-of-disease/8016072).

Peter van Wijngaarden from CERA said the new technology will test people who do not show any signs of memory impairment and detect abnormalities years before symptoms appear.

"At the moment, Alzheimer's disease is very difficult to diagnose," Dr van Wijngaarden said.

"Most people who present with memory impairment don't get access to a definitive diagnosis, because of the need for costly brain scans or a spinal tap to collect fluid."

**Next wave of treatments**

The test takes less than a second of imaging time so it is quick and easy, Dr van Wijngaarden said.

"The new type of imaging uses different colours of light and we can detect abnormal proteins that build up product in the back of the eye," he said.

Dr Xavier Hadoux, who helped develop the technology, said it had the potential to revolutionise the diagnosis of Alzheimer's disease.

"The test can identify people at risk of the disease and open the way to new treatments and hopefully a cure," Dr Hadoux said.

"Ultimately, we hope the people who are identified may go on to the next wave of treatments, so they never develop the disease."

*Source: ABC News Canberra, Saturday 1/6/2019.*

## Replacing retinal pigment epithelial cells

Retinal pigment epithelial (RPE) cells have a number of important jobs, including looking after the adjacent retina. If these cells stop working properly due to damage or disease, then certain parts of the retina die. As the retina is the component of the eye responsible for detecting light, this leads to the onset of blindness. RPE cells can be damaged in a variety of diseases such as: age-related macular degeneration (AMD), retinitis pigmentosa and Leber’s congenital aneurosis.

One way to treat these diseases would be to replace the damaged RPE cells with transplanted healthy cells. Unfortunately, it is not possible to take healthy RPE cells from donors so it is necessary to find another source of cells for transplantation. Scientists have recently produced new RPE cells from both embryonic stem cells and iPS cells in the lab. The safety of embryonic stem cell-derived RPE cells has been tested in phase I/II clinical trials for patients with Stargardt’s macular dystrophy, and for those affected by AMD by a stem cell biotech company called Advanced Cell Technologies. The[results of the trial, published in 2014](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(14)61376-3/abstract) , demonstrated safety and showed engraftment of the transplanted RPE cells. However, some participants experienced adverse side effects from the immunosuppression and the transplantation procedure itself. Interestingly, despite not being an endpoint of this trial, several patients also reported an improvement in vision.

A second Phase I/II trial exploring [the use of RPEs derived from human embryonic stem cells for people with wet AMD](http://www.insight.mrc.ac.uk/2014/02/20/pete-coffey-driving-stem-cells-to-the-clinic/)  is currently underway in the United Kingdom. The first patient received their transplant in September 2015. This work, led by Prof Pete Coffey, is ongoing and is being carried out at Moorfields Eye Hospital as part of the London Project to Cure Blindness.

Finally, Japanese researcher, Dr Masayo Takahashi is leading a clinical trial in Japan which transplants RPE cells made from iPS cells into patients with wet AMD. The trial was put on hold for several months due to regulatory changes in Japan and concerns about mutations in an iPS cell product to be used in the trial. The trial has recommenced June 2016 and many await the results.

There are [several other phase I or I/II clinical trials using pluripotent stem cells world-wide](http://www.nature.com/nrd/journal/v14/n10/fig_tab/nrd4738_T1.html) involving small numbers of participants. These trials are examining primarily the safety, but in some cases also the effectiveness, of the use of RPEs developed from pluripotent stem cells in dry and wet AMD and Stargardt’s macular degeneration.

Replacement of damaged RPE cells will only be effective in patients who still have at least part of a working retina, and therefore some level of vision (i.e. at early stages of the disease). This is because the RPE cells are not themselves responsible for ‘seeing’, but are actually responsible for supporting the ‘seeing’ retina. Sight is lost in these types of diseases when the retina begins to degenerate because the RPE cells are not doing their job properly. So the RPE cells need to be replaced in time for them to support a retina that is still working. It is hoped that transplantation of new RPE cells will then permanently halt further loss of vision, and in some cases may even improve vision to some degree.

**Replacing retinal cells**

In many of the cases where vision is lost, we often find that the problem lies with malfunctioning retinal circuitry. Different disorders occur when particular, specialized cells in the circuit either stop working properly or die off. Despite the retina being more complicated than other components of the eye, it is hoped that if a source of new retinal cells can be found, we may be able to replace the damaged or dying cells to repair the retina. In addition, this approach may also help to repair damage caused to the optic nerve.

Again, scientists have turned to stem cell technology to provide the source of replacement cells. Several studies have now reported that both embryonic stem cells and iPS cells can be turned into different types of retinal cells in the lab. Within the eye, a type of cell called the Müller cell, which is found in the retina, is known to act as a stem cell in some species, such as the zebra fish. It has been suggested that this cell may also be able to act as a stem cell in humans, in which case it may provide another source of retinal cells for repair of the retina.

Unlike RPE cell transplantation, direct repair of the retina may allow patients who have already lost their vision to have it restored to some degree. This gives hope for patients with disorders like late-stage age-related macular degeneration, where the light-sensitive photoreceptor cells in the retina have already been lost. This type of research may also provide new treatments for people who suffer from retinal diseases like retinitis pigmentosa and glaucoma. However, despite encouraging evidence, such research is very much in its infancy. There are currently no patient clinical trials planned using this type of approach, as significant further research is still required first.

In the Future

Stem cell technology holds great potential for improving the lives of people who suffer from visual disorders. A number of studies are currently being undertaken in order to develop new therapies to treat, and/or prevent a loss of vision. Central to this research is the development of our understanding of how different types of stem cells behave, and how best to harness their potential in the eye. A tailored approach is required, dependent upon the particular problem a patient is experiencing. Stem cells are not a one-stop, generic cure, but they do hold exciting potential for the production of new biological components that can be used to repair the eye.

*Source: Eurostemcell*

# Monthly Programs

## Audio Book group

This group meets monthly on the first Wednesday of each month to discuss the audio book of the month. RSVP to Bob James on 6296 2644 or 0408 474 916 or by email at [randjjames1@gmail.com](mailto:randjjames1@gmail.com) . Please note that there are no vacancies at present, please make contact to join the waiting list if you are interested in becoming a member.

## Braille group

If you would like to learn Braille or you would like support to continue your practice, we host a peer-supported Braille group for all levels of ability. For more information about Braille group contact Sharon Sobey on 6254 7326 or 0419 263 413 or koala@areujoking.com

**When**: every Thursday, 9.30 am – 11.30am

Please note that there are limited space at present, please make contact to ensure a place.

## Sense-Able Cooking

Sense-Able Cooking group is held on the third Friday of each month. The group aims to practise cooking skills, learn handy tips for cooking with vision impairment, and share favourite recipes. And eat delicious food, of course!

**When**: third Friday of the month

**Where**: Room 6, Griffin Centre, 20 Genge Street

**Cost:** $5 (for ingredients)

Please call CBS on 6247 4580 to reserve your place in this group.