*CANBERRA BLIND SOCIETY (CBS)*

*July 2020 Newsletter* 419

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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 five percent of your purchases made on food and beverages in the public restaurants, bars and grills are included. |

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# From the President’s Chair – Peter Granleese

Welcome to the July issue of The CBS Newsletter and the halfway mark for 2020. It has been a challenging time over the last six months, with the lockdown period caused by COVID-19 taking up most of the time.At the beginning of the year, CBS was riding high having received the good news that its application for a grant under The National Disability Insurance Scheme (NDIS) 2020 / 2023 Information, Capacity and Linkages ILC Funding Round had been successful. The money involved is significant and together with a previous grant under the 2019 / 2020 ILC funding round, will place The Society on a secure financial footing until the middle of 2024.

It was with much anticipation therefore that we commenced the year with plans to increase the range of services, made possible in part by the appointment of an Outreach Officer to provide information and advice, assessments, counselling, referrals, training in daily living skills and ongoing assistance for those people with changing needs. The appointment of the Outreach Officer has been delayed due to the lockdown and we now hope to have the position filled by the middle of August. By that stage, face to face contact involving individuals on a one to one basis will be allowed providing social distancing is observed. We are not able to say at this stage when group activities will recommence due to the lack of space at CBS that is required to observe social distancing.The Book Club and Braille Group have continued online, thanks to Bob James and Sharon Sobey, while the Cooking Group has not met since the lockdown. Our social gatherings held throughout the year have also been affected namely, The Easter Parade and Christmas in July, while there is a question mark as to whether Melbourne Cup and Christmas Lunches will go ahead this year.On a more positive note, The Society continues to develop the organisational capacity that will enable it to increase services once the Outreach Officer is appointed. The CBS data base is being updated by CBS volunteers to determine whether the 380 clients registered still require our assistance. An up to date data base will provide a good starting point for the Outreach Officer.Funding from the two ILC grants have been a lifesaver for CBS, enabling us to re build The Society’s organisational capacity following the withdrawal of services by our partners from The Royal Society for The Blind in August 2017. Commencing with the appointment of Glenn Doney in August 2019 to manage the process, a core group of vision impaired volunteers have been recruited to assist in the day to day running of The Society.Under the terms of the two ILC Grants, CBS is committed to run a series of workshops for vision impaired volunteers interested in participating in its running. These workshops will cover the role of CBS in The ACT, including its aims and objectives, general administration, policy and program development, advocacy and peer support and governments, including the role of The CBS Board. Although funding for these workshops has been provided to train vision impaired volunteers, we welcome sighted individuals who are interested in attending and becoming a CBS volunteer. Sighted volunteers can do many things that a vision impaired volunteer cannot do so their assistance is crucial for a remerging CBS.

With the easing of restrictions, it is planned to commence these workshops in mid-August using facilities in The Griffin Centre that will allow for social distancing. The first workshop will cover the history and role of CBS in The ACT and the part volunteers play in its running. If you are interested in the work of CBS and would like to become one of our growing band of volunteers, we would like to hear from you. Volunteers perform many tasks at CBS and we are certain there is a task just waiting for you.

As previously mentioned, one of the conditions for receiving ILC funding is the requirement that the vision impaired community plays a leading role in the design and monitoring of our services to insure that they are meeting community’s needs. CBS has established The Consumer Reference Group (CRG) as its mechanism for providing independent advice on the needs of our community. The CRG will be made up of management, volunteers, clients and other stakeholders to monitor CBS services to see if they are meeting their objectives, undertake research, identify the need for new services and make recommendations to the CBS Board. The Terms of Reference setting out the makeup and role of the CRG, is available from CBS on request. We are seeking expressions of interest from at least five representatives from the blind or low vision community to make up the majority of The CRG. If you are a person with lived life experiences dealing with the effects of blindness and have a general knowledge on the needs of our community, we would like to hear from you. If you are interested, please call us at CBS and we will send you a copy of The Terms of Reference. For more information contact Glenn on 041 331 0787 or email [canblind@canberrablindsociety.org.au](mailto:canblind@canberrablindsociety.org.au)

# New typeface trial for the Newsletter

A new typeface – greater legibility and readability for low vision readers

Atkinson Hyperlegible font is named after Braille Institute founder, Robert J. Atkinson. What makes it different from traditional typography design is that it focuses on letterform distinction to increase character recognition, ultimately improving readability. The Braille Institute are making the typeface free for all to use. You can download the typeface to your computers here: <https://www.brailleinstitute.org/freefont>. Please let us know what you think of the new typeface – previously we used Arial.

# Braille Transcription

Sharon Sobey who helps the facilitate the weekly braille class is offering a braille transcription service for anyone wanting documents transcribed into braille. She can transcribe any electronic document of any size into braille. The service consists of the creation of documents into UEB or old Australian grade one or two and includes proofreading of documents. Sharon will charge for the cost of braille paper and an hourly rate which is negotiable. For more information, please contact Sharon on 0419 263 413 or 6254 7326.

**Radio 1RPH Update**

There is movement at the station and it is all good for our listeners. During the COVID19 emergency COVID19 Radio 1RPH has been able to keep our well-loved programs on the air and make some innovative changes. This is due to the foresight of our Board and the skills of our volunteers. The morning live news reading for both Canberra and Wagga Wagga and Junee has continued with a 2-hour program from 7 am to 9 am. The evening news has been reduced to one hour from Monday to Friday. A new format for the evening news readings is being developed.

Radio 1RPH volunteers are using their skills and modern technology to record programs from home. We are very excited at the quality of the home recordings which our volunteers are providing. Radio 1RPH is learning to use the flexibility offered by home recording to offer our listeners a wider variety of programs. Our newly formed Program Team is seeking ideas from listeners and volunteers for new programs. All ideas will be considered but we have to take account of our available volunteer resources. You can email your suggestions to [programteam@radio1rph.org.au](mailto:programteam@radio1rph.org.au) or phone Jenni at the station on 6241 4076.

Radio 1RPH now has access to the catalogue of programs offered by the Community Radio Network. If you have heard something on a community radio station that you would like to hear on Radio 1RPH please let us know by contacting the Program Team or phoning the station.

Listen to Radio 1RPH at 1125 am on the AM dial, via the tune in radio app or via the listenlive link on our website <http://www.radio1rph.org.au>

# The Way I see It – Graham Downie

Since the ACT Government embarked on the light rail between Civic and Gungahlin, Canberra bus users have been treated as second-class travellers.

Never more so than the recent announcement that $12 million would be spent on a light rail stop at Mitchell. Less than half of Canberra’s bus stops have any shelter, and most of those which do, provide only limited protection from the city’s climate extremes.

This is not to suggest there should be no tram stop at Mitchell. Indeed, it should have been provided as part of the original project, though, of course, the original project is more about feathering the nest of developers and government coffers than improving Canberra’s lamentable public transport.

But the question which demands an answer is how a tram stop can cost $12 million. For that money, at $500,000 each, the government could provide 24 houses. Overdue it might be, but what are Mitchell commuters getting which bus passengers can only dream of?

The $1 billion or so spent building the 12km light rail track and rollingstock would have made an enormous difference if spread across the entire Canberra public transport service. But having spent money on a project, not supported by any independent analysis, the ACT government seems determined to lavish even more money on it to pander to the Greens, its political partners, who demanded the tram in return for its support of Labor.

Meanwhile, with the introduction of the tram, many direct bus services were discontinued, increasing travel time to the vast majority of public transport users who are not served by the tram. Distances between many bus stops were increased and some quite direct bus routes were redesigned, effectively doubling travelling time. Notably route 56, which takes hapless Fyshwick shoppers and workers on a tour of South Canberra. Civic to Barrier Street alone takes 42 minutes, with another 10 minutes to orbit the suburb.

Further, in a cynical attempt by transport planners to prop up the government’s tram without regard for convenience of bus passengers, two bus shelters in Wattle Street Lyneham, adjacent to the Lyneham shops, were forsaken by route 50, leaving shoppers a walk of about two blocks to the main shopping area. There is no shelter between the new stops and the shops and no shelter at the relocated bus stops.

The reason for this inconvenience, drawn to planners’ attention before the change, was to encourage people in Wattle Street, east of the shops, and in Goodwin Street, to use trams instead of buses. Never mind those needing to travel to the Dickson group centre are not served by the tram and have to walk further for a bus. Lyneham High School students also lost their bus service.

In May, Greens transport spokeswoman Caroline Le Couteur, whose party effectively forced the tram on us, saying the Greens are committed to fixing the problems caused by the 2019 April bus changes. She could begin by urging the restoration of the service to Lyneham shops and the restoration of direct bus service between Kaleen/Giralang and the city. This service was cut, also to force people on to the tram. As predicted, this has resulted in reduced public transport use by these residences. And how about addressing the reduced weekend bus timetables, which see many suburbs with the worst bus services for more than 50 years.

Some weeks ago, a thoughtful bus driver said the southbound stop had been moved even further from the shops. This information was apparently conveyed by a sign on the former stop. More than three weeks later, there has been no response to my phone call to Transport Canberra to clarify the position of the new stop. Neither has Transport Canberra revised information on NXTBUS, which still shows stop 1743 at Lyneham Primary School is served by route 50.

Public transport, especially to many people with a disability, is a primary means of getting around this city, but largely for political reasons, the needs of the majority are disregarded with the motive of boosting passengers on the tram by deliberately inconveniencing bus passengers.

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# Medical News

**AI-supported test for very early signs of glaucoma progression**

**May 3, 2020 - University College London**

A new test can detect glaucoma progression 18 months earlier than the current gold standard method, according to results from a UCL-sponsored clinical trial.

The technology, supported by an artificial intelligence (AI) algorithm, could help accelerate clinical trials, and eventually may be used in detection and diagnostics, according to the Welcome-funded study published today in Expert Review of Molecular Diagnostics.

Lead researcher Professor Francesca Cordeiro (UCL Institute of Ophthalmology, Imperial College London, and Western Eye Hospital Imperial College Healthcare NHS Trust) said: "We have developed a quick, automated and highly sensitive way to identify which people with glaucoma are at risk of rapid progression to blindness."

Glaucoma, the leading global cause of irreversible blindness, affects over 60 million people, which is predicted to double by 2040 as the global population ages. Loss of sight in glaucoma is caused by the death of cells in the retina, at the back of the eye.

The test, called DARC (Detection of Apoptosing Retinal Cells), involves injecting into the bloodstream (via the arm) a fluorescent dye that attaches to retinal cells, and illuminates those that are in the process of apoptosis, a form of programmed cell death. The damaged cells appear bright white when viewed in eye examinations -- the more damaged cells detected, the higher the DARC count.

One challenge with evaluating eye diseases is that specialists often disagree when viewing the same scans, so the researchers have incorporated an AI algorithm into their method.

In the Phase II clinical trial of DARC, the AI was used to assess 60 of the study participants (20 with glaucoma and 40 healthy control subjects). The AI was initially trained by analysing the retinal scans (after injection of the dye) of the healthy control subjects. The AI was then tested on the glaucoma patients.

Those taking part in the AI study were followed up 18 months after the main trial period to see whether their eye health had deteriorated.

The researchers were able to accurately predict progressive glaucomatous damage 18 months before that seen with the current gold standard OCT retinal imaging technology, as every patient with a DARC count over a certain threshold was found to have progressive glaucoma at follow-up.

"These results are very promising as they show DARC could be used as a biomarker when combined with the AI-aided algorithm," said Professor Cordeiro, adding that biomarkers -- measurable biological indicators of disease state or severity -- are urgently needed for glaucoma, to speed up clinical trials as the disease progresses slowly so it can take years for symptoms to change.

"What is really exciting, and actually unusual when looking at biological markers, is that there was a clear DARC count threshold above which all glaucoma eyes went on to progress," she added.

First author Dr Eduardo Normando (Imperial College London and Western Eye Hospital Imperial College Healthcare NHS Trust) said: "Being able to diagnose glaucoma at an earlier stage, and predict its course of progression, could help people to maintain their sight, as treatment is most successful if provided at an early stage of the disease. After further research in longitudinal studies, we hope that our test could have widespread clinical applications for glaucoma and other conditions."

The team is also applying the test to rapidly detect cell damage caused by numerous conditions other than glaucoma, such as other neurodegenerative conditions that involve the loss of nerve cells, including age-related macular degeneration, multiple sclerosis, and dementia.

The AI-supported technology has recently been approved by both the UK's Medicines and Healthcare Products Regulatory Agency and the USA's Food and Drug Administration as an exploratory endpoint for testing a new glaucoma drug in a clinical trial.

The researchers are also assessing the DARC test in people with lung disease, and hope that by the end of this year, the test may help to assess people with breathing difficulties from Covid-19.

DARC is being commercialised by Novai, a newly formed company of which Professor Cordeiro is Chief Scientific Officer.

**Glaucoma could be successfully treated with gene therapy**

April 21, 2020 – University of Bristol

A new study led by the University of Bristol has shown a common eye condition, glaucoma, could be successfully treated with a single injection using gene therapy, which would improve treatment options, effectiveness and quality of life for many patients.

Glaucoma affects over 64 million people worldwide and is a leading cause of irreversible blindness. It is usually caused by fluid building up in the front part of the eye, which increases pressure inside the eye and progressively damages the nerves responsible for sight. Current treatments include either eye drops, laser or surgery, all of which have limitations and disadvantages.

The research team led by academics at the Bristol Medical School: Translational Health Sciences tested a new approach that could provide additional treatment options and benefits. Their findings are published in the journal Molecular Therapy.

The researchers designed a gene therapy and demonstrated proof of concept using experimental mouse models of glaucoma and human donor tissue.

The treatment targeted part of the eye called the ciliary body, which produces the fluid that maintains pressure within the eye. Using the latest gene editing technology called CRISPR, a gene called Aquaporin 1 in the ciliary body was inactivated leading to reduced eye pressure.

Dr Colin Chu, Visiting Senior Research Fellow in the Bristol Medical School: Translational Health Sciences and corresponding author, said: "Currently there is no cure for glaucoma, which can lead to loss of vision if the disease is not diagnosed and treated early.

"We hope to advance towards clinical trials for this new treatment in the near future. If it's successful it could allow a long-term treatment of glaucoma with a single eye injection, which would improve the quality of life for many patients whilst saving the NHS time and money."

The academics are currently in discussion with industry partners to support further laboratory work and rapidly progress this new treatment option towards clinical trials.

# Audio Book Club – Bob James

The audio book group continues to meet by tele link and the August book will be "The Muse" by Stephanie Bishop, on Wednesday 5th.

In August we may find a way to meet face to face in our usual place, the CBS Office, this will depend on space available and any changes to the Covid-19 restrictions.

For information contact Bob James on 6296 2644.