

Newsletter

December 2021



Welcome!

Hearing loss affects people in varying ways and we hope to be able to support and encourage people on their hearing loss journey.

Lockdown is over, but we are all still aware of the implications of the changes Covid has made to our lives. We are being updated about additional streams that are coming to Australia.

Many Canberrans, particularly we hearing impaired, are still conscious that we still need to take care. Most still prefer to have limited contact with a lot of people.

We have missed families and friends interstate and overseas, and still have concern for them.

We hope at Christmas time, we may be able to reconnect with these special people, who we have so missed this past year.

Many of our BHAC Members have health issues, so thoughts and prayers are with them.

Wearing masks has been more difficult for we hearing impaired. As soon as I put the elastic around my ears, the hearing aids come out, so one has to be extremely careful. One lady I have heard of, has lost 3 aids.

A very special BHAC Member, Janet, posted me an aid with elastic which goes around my head. It has been fantastic, as I can wear it around my neck and just pull up when required.

Although health professionals and others can lower the mask to talk to a hearing impaired or Deaf person, few seem to do this.

Please contact me on 0410 463 761 or email carol.taloni@gmail.com for support or information. Or just to advise you would like a chat!!!! And I will return call or email.

Please let me know if you want to be involved in future events.

On behalf of the BHAC Executive Committee, I wish you all a very Happy Christmas and a Special Year in 2022.

Best wishes

Carol Taloni
President BHAC



Rediscovering Music Program

I am delighted to advise that we will have three Rediscovering Music Sessions in 2022.

The Canberra Symphony Orchestra (CSO) has confirmed the dates that the Presenter, Kristen Sutcliffe and Musicians can be available.

We will be having the RDM Program at the Hellenic Club. CSO and Better Hearing Australia Canberra (BHAC) will be promoting the Sessions.

There will be two sessions at 2pm and 5:30pm. Dates are:
Tuesday 1 March 2022
Tuesday 24 May 2022
Tuesday 27 September 2022

More information will be provided in 2022.

BHAC AGM

The AGM was held on Saturday 27 November 2021 at 10:30am.

The AGM should have been held in May 2021, but due to Covid, we had sought an extension.

The AGM for 2022 will be held in May 2022.

Sadly, apart from 5 members of the existing Committee Members in 2021, only Sue and Haydn Daw were in attendance.

I received no new Nominations. The 2021 members of Executive Committee renominated and were elected unopposed.

President:	Carol Taloni
Vice President:	Ricky Chung
Secretary:	Heather Irons
Treasurer & Public Officer:	Priti Narayan
Committee Member:	Judy Greenfield

I would like to thank the Executive Committee, which included

Gemo Virobo for their support of me, and their dedication to continuing the work of BHAC, during the difficult time we experienced during Covid and lockdown.

Three of the six people do not have a hearing loss, yet spend many hours working to support we hearing impaired. They are to be commended for their support.

Ricky and Priti both work full-time and as well, are currently starting up their own businesses. Ricky had to rebuild the website and Priti has managed the financial accounts to present to the Auditor.

Heather has provided the Minutes of all the meetings held and the AGM, whilst working full-time.

Judy has managed the payment of the accounts with my support. It has been a difficult year for Judy, as she has been back and forth to Sydney, caring for her elderly Mother. In Sydney, Judy has had to go to her sister's home to use the internet and to her brother's home, to be able to join the AGM by Facetime. Many thanks to her family for their support.

She has been a great support to me in our Hughes Office, when we had to move to a new room.

My personal thanks to an amazing Executive Committee.

The Executive Committee will have a Planning Day in January 2022 to discuss arrangements for events during the year.

Coffee Morning at COTA in Hughes

On Monday 2 August 2021, I organised a Coffee Morning, which was an opportunity for Members to get together. Due to Covid, I was only able to have 8 attend in the Board Room.

It was a very successful get together.

My intention was to continue during the following months, offering the opportunity to other BHAC Members to join together and meet others.

Sadly Covid Lockdown intervened and no more were able to be held.

I will recommence them in February 2022. At this time, numbers are still restricted in the rooms at Hughes, so have to make personal invitations to ensure the allowable numbers, rather than just make it an open invitation to all.

Hearing Loss Management - Lip Reading Classes

No definite arrangements have been made for the Day Classes in 2022. Some people do not want to go back to a group situation at this time.

I have been conducting a class all year via Zoom, on Thursdays, which has been very successful. It has been an important part of having social interaction with lots of talking, laughter and emailed homework completed, so we had sentence practice.

Susanne was minding her granddaughter, Aurora, last Thursday, so she popped in to give her apologies and say Hello to all. We all waved to Aurora and we had a surprise return wave. She must have wondered what was going on!!!!

Many thanks to Linda Dwyer for conducting the evening classes in 2021. Linda will be holding Classes at 5:30pm Tuesdays in the Hellenic Club. Contact Linda on 0417 696 583 or email ldwyer@grapevine.com.au

More information will be provided in 2022.

BHAC Annual Dinner

Delighted to advise that I have booked the Hellenic Club for the Annual Dinner, which will be held on Tuesday 29 November 2022.

Sadly the last dinner we had was in 2019, as 2020 and 2021 had to be cancelled.

COTA

Thank you to CEO of COTA, Jenny Mobbs, for her personal support and that of her Staff during 2021. Jenny kindly waived a portion of our Rent, as due to Covid, we were unable to use the office.

We look forward to being able to participate in their events in 2022.

Sound Bars

BHAC Member Anne, queried me on Sound Bars, as she was having an issue with equipment she had. I could not find helpful information for her. Anne has some information which may be of interest to other Members. Anne advised that she invested in a good quality three speaker Sound Bar that comes with a separate woofer. She reports she is hearing the TV better with the sound bar, than she did when using her 'blue tooth gismo'. She has been able to turn the bass way down, which is the greatest advantage. Anne said the Salesman indicated that a hearing impaired person needs good separation on the two treble speakers with sound bar. Anne is extremely happy with the results from her purchase.

Birdsong

Something a little different for this end-of-year issue; the bird depicted on the front cover is the aptly-named blue-footed booby.

“Blue-footed boobies make raucous or polysyllabic grunts or shouts and thin whistling noises. The males of the species have been known to throw up their heads and whistle at a passing, flying female. Their ritual displays are also a form of communication. Mates can recognize each other by their calls. Although calls differed between sexes, unique individual signatures were present. Both males and females can discriminate the calls of their mates from others.”

(Source: Retrieved from: https://en.wikipedia.org/wiki/Blue-footed_booby)

There is concern that the population of these unusual birds is in decline in the Galapagos Islands. The front cover image was sourced from <https://bluefeetfoundation.com/about-me>

Hearing Loss Journey (Ann Lam)

My hearing loss journey started in 2008. I remembered everything was normal at 10am one day as I went about my routine. Then I started thinking it was a bit strange that the traffic noise outside sounded as though it was coming from far away. I tried unblocking my ears like yawning as one would do when one is on the plane but nothing worked. By noon when I was having lunch and watching TV, I realized that the sound from the TV sounded softer and very remote too. Upon some investigation, I found that my left ear was totally deaf.

I rang my GP and the earliest appointment I could make was for the following day. I rang the nurse helpline and all the advice I got was 'not to worry, it is probably wax'. I had an outing that afternoon and my friend said 'not to worry, just come and take your mind off your problem'. I went and all along I knew I was not feeling well. I was just so lucky that I managed to drive home. By the time I got inside the door about 4.30pm, I started having vertigo and I knew I had to ring for the ambulance. The ambulance came and after giving me some intravenous injection, I was taken to hospital.

It took a long time to get me admitted and examined by doctors. I think the next day, the ear-nose-throat specialist came and said it could be a bacterial or viral infection. With one I might recover from hearing loss and one I probably could not. I remembered thinking I hope he knew what treatment to give me and I hope I'll regain my hearing. It is strange to think back now how I was more worried about my hearing loss than I was in a vertigo state. I had one previous vertigo experience a few years before (reason unknown) and I had recovered, so I thought I would be OK. I think the one thing that kept me going at the time was a hope that my hearing would recover. Sometimes ignorance is a blessing as some people say! My vertigo was not improving and I could not move my head at all without having another bout of vomiting. All I could do was to lie perfectly still like a vegetable for the next few days. I had lots of Maxilon injections to stop me vomiting whenever I needed to move. They gave me a MRI scan and said I was not having a stroke and they also got me to do the Epley manoeuvre exercise which made me even sicker for the next 24 hours.

After 2 weeks I still had very limited head movements without getting sick and the vertigo was controlled only by the Maxilon medication. I could walk only if I did not move my head. If I moved my head, I would just lose my balance and stumble. The hospital said there was nothing else they could do for me and discharged me. The discharge summary said I had labyrinthitis.

I saw 2 specialists – one being the treating specialist at the hospital. Both said it was unlikely I'll regain my hearing and that eventually my body will compensate for the loss of one ear and I should be able to walk normally. I also had a hearing test and apart from profound deafness on the left ear, everything else seemed normal.

It is still a mystery of how I contracted the virus, assuming it was a virus. I do not swim and did not have a cold around the time when the episode happened.

I never regained hearing on the left ear and it developed tinnitus soon after I left the hospital, but noises sound normal rather than being remote. When the environment is noisy, my tinnitus is worse and I feel more 'dizzy', so it takes a lot more effort to keep my balance. When it is completely quiet, I don't have tinnitus, at least not noticeable.

I tried some balance therapy, but it did not help with my feeling of dizziness. I even tried an alternative music therapy in the first few months, supposedly good for autistic children, but it just made me feel worse and so I stopped. I did a lot of balancing exercises in the gym which helped my balance, but I always had trouble whenever I moved my head and this continues even today. I find noises affect my balance - going to the mall, being in a car or any public transport would send me unsteady on my feet. The problem is worse if I am tired.

The loss of hearing on one ear is not affecting my life much, but the loss of balance and the feeling of 'dizziness' is very hard to get used to. As I get older, the condition is getting harder to compensate because somehow the brain must work a lot harder.

In 2008, my ENT specialists said I could have a BAHA system to help with the hearing loss, but a cochlear implant was not recommended since I had a good ear and my brain would

probably ignore the signals coming from the implant. It would be like we choosing to look at a colour TV rather than a black and white one given the choice. However this thinking might be different since that time and the cochlear might help with my tinnitus and dizziness apart from the hearing itself.

In 2015 I discovered the Phonak CROS system. It looks like 2 normal hearing aids. It is essentially a 'microphone' on my deaf ear picking up all the sounds from that side and transmitting the sound to the 'receiver' on the other ear. It is good that it helps to pick up more sound, but it is not discriminatory of what it picks up. Sometimes it does not pick up what someone says who is standing right next to my deaf ear, but it will pick up the rustling noise someone in the vicinity makes while fiddling with their bags. As some of the noise is 'transformed' as a normal hearing aid does (I believe) and the noise is amplified, I had to learn what a particular sound sounds like e.g. how the home security system sounds like with the hearing aids on. As I am unable to hear where a sound originates from, it is challenging at times e.g. I found out a particular sound was coming from the person sitting next to my deaf ear scratching their leg! I feel that the extra noise coming to the good ear increases the effort my brain has to cope with. I seldom use the CROS system now unless I am in a gathering where I cannot choose where to position myself. Obviously one needs to assess the benefits of the CROS system according to their own circumstance.

I want to acknowledge and thank Professor David Ryugo for all the information and advice he has kindly given me.

Some of the advice was we should investigate our options and not be embarrassed to ask professionals questions, and we should all try our best to have an active and healthy life style.

Note. I am aware that one should wear their hearing aids all the time. I checked with my audiologist when I bought my CROS in 2015 whether I should wear it all the time and she said I didn't need to as the CROS was not doing anything for my deaf ear and my other ear was normal and did not need a hearing aid. When my good ear needs a hearing aid for itself in the future, then the CROS can be programmed to cater for that as well (and then I'll need to wear the aid all the time). Unfortunately I think most software for hearing aids will be too old after a few years and I'll probably need new ones.

Professor David Ryugo's reply to Ann (and Carol)

Dear Ann and Carol

Thank you both for sharing your “inner ear” story with me. You are both dealing with loss of an ear and dizziness with incredible grace. Your story encourages me to keep working on our projects and trying to understand how the ear and brain work. I also want to report that I have not been successful in getting the name of a vestibular physiotherapist in Canberra but was advised that a neurologist with experience with dizziness might be the way to go. I think covid has slowed everything down as my audiology friends who work with hearing and balance say that clinic visits have dropped significantly as have meetings to discuss science and clinical problems. With the opening up of society and with greater vaccination rates, these things should change.

I am working on a manuscript addressing sudden sensorineural hearing loss, an affliction that has no known cause and generally affects only 1 ear. When we finish the piece, I'll be sure to send you a version to see if it is informative. I'm trying to keep it readable for the general public but it might still be too specialized. Maybe I can write a second piece that is more user-friendly for the BHA Newsletter.

In the meanwhile, keep well. Best,
David

Professor David Ryugo's comments re Carol Taloni's Story

Carol was told her sudden hearing loss may have been due to a virus, but she was not sick at the time. So very interesting to receive the diagnosis from Professor David Ryugo:

Dear Carol

I hope this note finds you well. And thank you for including me

with the BHAC Newsletter. Your description of your hearing loss seems like what is known as idiopathic sudden sensorineural hearing loss. It is a rare phenomenon, occurring in 5-30 out of 100,000 people. It is called idiopathic because there is no known cause although there is a list of more than 200 possibilities. The most common presumed causes are an inner ear membrane rupture from pressure or head injury, a viral infection, a small stroke, or some sort of inflammatory reaction. Because of spontaneous recovery--estimated at 35-65% full recovery and another 10% with some recovery--the true incidence is unknown. It sounds like you are one of the unlucky 30% where the loss is permanent. The standard treatment today is steroids--either systematic (oral or intravenous) or an injection through the ear drum into the middle ear space. There is no direct evidence that any treatment helps. Ironically, because there is no evidence that steroids hurt (or at least, the risk of an adverse drug effect is low), doctors and patients continue to use steroids as treatment. I just happen to be working on a paper that describes the various treatment protocols, only to discover that the clinical approach is chaotic--different drugs, different doses, and variable means of measuring recovery--all are different so no study can be replicated. Please let me know if your doctors described your hearing loss as ISSNHL. I'll send you a copy of the paper when we finish it.

All the best,
David

Professor David Ryugo's comments about BPPV

Hi Carol

Thank you for your note. It sounds as if your friend with the dizziness has what is called benign paroxysmal positional vertigo. The crystals that are normally embedded in a membrane overlying the balance sensory cells sometimes get loose. Then they "rattle" around during head movements to cause the sharp loss of balance and vomiting. There are exercises one can do regularly to try to control the loose crystals. Neurospace [in Canberra] might actually be a place where they can teach you the exercises which might free you up for longer walks. I also went to

the link “neurospace.com.au” and after reading about them, got a really good vibe. I would go to them if I had a balance or motor problem--too bad they are so far away. But then, I’m hopeful that I won’t need to visit them. But they look good.

During an acute episode of dizziness, the treatment is putting the head gently into 6 different positions for a couple of minutes to let gravity settle the “loose” crystals into what is known as the vestibule, where they (hopefully) lie dormant and out of the way.

As you know, it takes special people with knowledge, kindness, and patience to deal with neurologic problems. Such problems are difficult and frustrating to treat, because there isn’t a pill to make things go away. It is too bad your friend’s GP was not very helpful. Unfortunately, there are plenty like that around--you just have to keep looking because there are good ones out there.

Yours truly,
David

Governance

BHAC Executive Committee

Carol Taloni	(President)
Ricky Chung	(Vice President)
Heather Irons	(Secretary)
Priti Narayan	(Treasurer)
Judy Greenfield	(Committee Member)

BHAC Advisory Panel

Professor David Ryugo	(Garvan Institute of Medical Research)
Anne-Marie Crowe	(Hear Life Audiology Canberra)
Edward Eyers	(Lawyerbank)
Vanessa Smith	(Lawyerbank)
Priti Narayan	(Chartered Accountant)

Contact

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Please note that the BHAC Office is not open every day. Please contact Carol Taloni on 0410 463 761 or email carol.taloni@gmail.com to make an appointment to meet, or to request further information.

Newsletter Editor: Carol Taloni

Disclaimer: Please note the opinions expressed are only those of the Editor. Please seek medical advice regarding any issues relating to ear disease or hearing loss.

BETTER HEARING AUSTRALIA CANBERRA INCORPORATED

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Phone 6281 3962 Email: bhacanberra@gmail.com

Website: www.bhacanberra.org



MEMBERSHIP RENEWAL FOR THE 2022 YEAR

Given Name:..... Family name:

Address : Street/PO Box

Suburb State..... Postcode

Email:

Telephone:.....Mobile:

Severity of hearing loss:

Please indicate type and number of Hearing aid(s)/Cochlear Implant(s)

Your membership indicates that you have an affinity with the work that we do. This is a very important signal to your Committee. We are always keen to hear from members about the direction and scope of our work. If you also wish to make a tax deductible donation towards our work, this will help us do more.

Payment can be made by direct credit transfer, or cheque or arrangement to meet at the BHAC Office to pay by cash.

PAYMENT DETAILS

Membership of BHA Canberra	Individual	\$20 (1 January 2022 to 31 December 2022)
	Joint	\$25 (1 January 2022 to 31 December 2022)

Insert name of partner if both joining

.....

How you can pay:

1. **By Direct Credit:** to BHA Canberra's CBA account (**quoting initial and surname**)
BSB: 062 907 Account: 1032 4198
2. **By mail:** send this form **and cheque** to BHA Canberra, PO Box 119, DEAKIN WEST ACT 2600

**BHA is an organisation of volunteers
Supporting people with hearing loss**

We welcome your membership to BHAC