



- NEWSLETTER -

February 2021

Better Hearing Australia - Canberra

Welcome!

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

2020 was a very difficult year for us all. The lifestyle we knew will never be the same.

We have had many challenges to face and options to be decided. Hearing loss adds another dimension to these. Not being able to have face to face consultations made communication very difficult.

One could not follow their normal lifestyle pattern.

Being advised to stay indoors was the best option in the face of COVID-19. But it meant isolation for a lot of people.

Canberra has been fortunate in our outcomes.

BHAC was unable to hold many activities during the year. We hope to provide some interesting events and we are hoping that you will patronise them.

I hope you enjoy this issue!

Carol Taloni
President



Professor David Ryugo

Professor David Ryugo is on our BHAC Advisory Panel.

Understanding how we experience sound and what that means for hearing loss and hearing restoration is Professor David Ryugo's specialty.

David earned a degree in Psychology from Yale University and a PhD in biological sciences from the University of California. He also spent nine years on the faculty at Harvard Medical School and was at Johns Hopkins University School of Medicine for 23 years. He retired as Professor Emeritus and joined the Australia's Garvan Institute as Head of Hearing Research.

David's research focuses on understanding brain mechanisms of hearing and studying the structure-function relationships in neuronal circuits of the auditory systems.

Professor David Ryugo has sent me an article 'Sound & Hearing Loss'. It is four very interesting pages. The Professor, in an email to me, said "Unfortunately, almost everything in this article is still relevant because progress in unraveling the problems of hearing loss has been slow."

If you would like to receive a copy to your email address, or would prefer a printed copy, please let me know.



Better Hearing Australia Canberra

BHAC Executive Committee

President: Carol Taloni
Vice President: Ricky Chung
Secretary: Heather Irons
Treasurer: Priti Narayan
Committee Members: Judy Greenfield, Gemo Virobo

Gemo Virobo is a Volunteer who joined our Committee in January 2021. Having younger ones on the committee has added to the expertise and history of BHAC that Judy Greenfield, Heather Irons and myself, have enjoyed for many years. Their professional skills, social media awareness and knowledge of the latest technical changes will be a great asset to all the members. Ricky Chung and Gemo Virobo will in the near future be providing us with a workshop where some of us hearing impaired who are not necessarily up with the latest in technology can learn on a one-to-one basis about Apps that are available. Priti Narayan, our Treasurer, is an expert in Financial and Tax Issues. Priti has her own Chartered Accountancy Business.

Upcoming events

We have planning in place for several get-togethers this year.

Hearing Loss - how does it all work?

Kristen Sutcliffe is an Audiologist at Hearing Australia and a Musician with the Canberra Symphony Orchestra. Kristen will have a Powerpoint Presentation. To ensure you can enjoy the Presentation, Polly Templeton is going to caption it as well. Because of COVID restrictions, it is essential that you contact Carol Taloni by phone or email to book your place. Kristen is going to be discussing Audiograms. She suggests you may like to bring your recent one for comparison.

Date: 19 February 2021

Time: 3pm

Venue: COTA Building (where BHAC Office is now situated). The Hall, 2 Wisdom Street Hughes, ACT 2605.

Rediscovering Music Program

Delighted to inform you that the Rediscovering Music Sessions are being continued this year.

Kristen Sutcliffe will be co-ordinating the Sessions with Musicians from the Canberra Symphony Orchestra. We are very grateful for their services and input. These sessions are greatly valued by those who have attended in the past. We hope those experiencing the session for the first time in this manner, will also appreciate the music.

Due to COVID, some changes have had to be made. We can no longer use the Conference Room at Holder for the afternoon session, due to numbers involved. The Hellenic Club has supported BHAC for many years. They give us the Room for the evening class 'in kind', in other words for free, and the same for the room and equipment for the BHAC Annual Dinner.

However, Clubs have been doing it extremely tough during this Covid period. At the Hellenic Club several rooms had had to be repurposed to suit their needs of compliance. So we have to pay for the hire of the room for these sessions. The BHAC Executive Committee has agreed to pay the \$800 for the hire of the room. So we need to ensure that they are well patronised.

The first date that RDM will be scheduled at the Hellenic Club is 4 May 2021. There will be a Session at 2pm. Second Session will be at 5:30pm. Further information will be provided closer to the date.

Hearing Loss Management - Lip Reading Classes

Classes recommenced on Tuesday 2 February 2021.

Linda Dwyer is taking the 5:30pm class at the Hellenic Club. Contact Linda on 0417 696 583 or ldwyer@grapevine.com.au

Carol Taloni has the class at the Grant Cameron Community Centre, Mulley Street, Holder. At present, class is at 2pm. Contact Carol on 0410 463 761 or carol.taloni@gmail.com

We discuss strategies on how to live with hearing loss in the normal world, and items that may help us in that world. The greatest benefit is sharing time with people who all have hearing loss. Those who understand exactly our feelings at times of frustration, depression, anxiety and lack of confidence. But we can also share all the good times. The friendships that can develop are very special and in my case, have continued for years.

The choice of the front cover image was inspired by the joy of hearing birdsong. It is intended to feature a different Australian bird on the cover of each issue of the newsletter. For this issue, the bird depicted is the Bellbird, or Bell Miner. Originally published in *Gould, J. (1848). The Birds of Australia*, these illustrations are available free of charge in the public domain.

The poem, Bell-Birds, by Australian poet Henry Kendall, is reproduced below.

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 issues.

Bell-Birds

By channels of coolness the echoes are calling,
And down the dim gorges I hear the creek falling;
It lives in the mountain, where moss and the sedges
Touch with their beauty the banks and the ledges;
Through brakes of the cedar and sycamore bowers
Struggles the light that is love to the flowers.
And, softer than slumber, and sweeter than singing,
The notes of the bell-birds are running and ringing.

The silver-voiced bell-birds, the darlings of day-time,
They sing in September their songs of the May-time.
When shadows wax strong and the thunder-bolts hurtle,
They hide with their fear in the leaves of the myrtle;
When rain and the sunbeams shine mingled together
They start up like fairies that follow fair weather,
And straightway the hues of their feathers unfold
Are the green and the purple, the blue and the golden.

October, the maiden of bright yellow tresses,
Loiters for love in these cool wildernesses;
Loiters knee-deep in the grasses to listen,
Where dripping rocks gleam and the leafy pools glisten.
Then is the time when the water-moons splendid
Break with their gold, and are scattered or blended
Over the creeks, till the woodlands have warning
Of songs of the bell-bird and wings of the morning.

Welcome as waters unvisited by the summers
Are the voices of bell-birds to thirsty far-comers.
When fiery December sets foot in the forest,
And the need of the wayfarer presses the sorest,
Pent in the ridges for ever and ever.
The bell-birds direct him to spring and to river,
With ring and with ripple, like runnels whose torrents
Are toned by the pebbles and leaves in the currents.

Often I sit, looking back to a childhood
Mixt with the sights and the sounds of the wildwood,
Longing for power and the sweetness to fashion
Lyrics with beats like the heart-beats of passion –
Songs interwoven of lights and of laughter
Borrowed from bell-birds in far forest rafters;
So I might keep in the city and alleys
The beauty and strength of the deep mountain valleys,
Charming to slumber the pain of my losses
With glimpses of creeks and a vision of mosses.

- Henry Kendall

Retrieved from: <https://allpoetry.com/Bell-Birds>

Your hearing loss journeys...

Sharing the story of your hearing loss journey may be beneficial to others. It can indicate how others have related to learning they have hearing loss.

Some were born with hearing impairment, so have had this journey from a very young age. Others have lost their hearing through illness or other medical issues. A lot of people have developed hearing loss with age. This can significantly impact one's life.

Many do not admit to having any loss of hearing, which continues to frustrate their husband, wife, partner, family members, work colleagues and friends. By denying such loss, we do ourselves a disservice, as we miss out on important things in life. Having the courage to admit 'Yes, I may need hearing aids or other support' takes courage. But we are the winners in the long run, as we do not isolate ourselves socially, but can continue to be part of life.

I had asked people individually over the years, if people would write their stories, but none were forthcoming. Helen Bridge broached the subject with me again, and I was delighted with those who completed the Survey I sent out, who indicated they too would let us share their journey. We hope we will be able to provide more stories in the coming months.

This issue's hearing loss journey comes from Helen. She would be very pleased to be in contact with others who may have otosclerosis. Helen has chronicled her journey in an amazing way. However, we may all not be as talented or have kept such meticulous records. So your story will be as interesting and important, in whatever manner it is written. Please contact me if you wish to be in contact with Helen, or if you want some help writing your story.



My Journey through Hearing Loss (Helen Bridge, age 76)

My hearing loss is due to the genetic condition Otosclerosis.

At age 16 I complained of 'blocked' ears. I was diagnosed with otosclerosis in 1964 at age 19.

Family background

My family lived in country NSW. Neither of my parents had hearing loss. I had a 'hard-of-hearing' grandfather and aunt. Neither wore hearing aids during my childhood ... we just talked very loudly to them!!!

In 2019, at an elderly aunt's funeral, I checked out my gathered cousins for hearing loss. Eight of my 14 cousins (all aged 50+) wore hearing aids. I assume they all had otosclerosis (since it runs in families). These cousins all developed hearing loss after the age of 30 and none had stapedectomy surgery.

I was diagnosed with otosclerosis in both ears at age 19. My older sister (my only sibling) was diagnosed with otosclerosis in one ear at age 32.

I had two successful and ever-lasting stapedectomies (left in 1968, right in 1977). My sister had one stapedectomy (in 1973) which failed after five years. (At the time I strongly advised her to see my specialist in Melbourne, but she chose to 'stay local').

1960-1964 (Stage 1 of my hearing loss journey) Aged 16 to 19

At age 16 (at the end of high school) I had a medical for my university scholarship applications. All was well. At the appointment I mentioned that my ears sometimes felt blocked. Probably catarrh was the GP's response.

I went to Canberra (ANU) in 1961, on scholarship to become a Secondary School teacher.

During that first year at university, I went to see a Canberra ENT specialist because my ears still felt blocked. He prescribed nose drops for my catarrh.

I sat in the front row of lectures, thinking that those sitting at the back didn't want to hear.

It never occurred to me that I had a hearing problem.

My fourth year of study required me to be in Sydney. My 'blocked' ears were worse in Sydney.

I realised that I actually couldn't hear properly so I went to see a Sydney ENT specialist.

He diagnosed **Otosclerosis**. He told me it was a progressive, inoperable deafness.

He predicted that I would be 'stone-deaf' by the time I was 30.

His advice was to quit my teacher training now because I wouldn't pass the end-of-year medical for teaching.

He advised me to get a hearing aid, learn to lip read and find a new career path.

I went home to my country family, with a hereditary deafness that my family had never heard of.

1964-1968 (Stage 2 of my hearing loss journey) Aged 19 to 24

I got a hearing aid, went to lip reading classes. And I got lucky!!!!

When considering job possibilities, I spoke with an ANU Professor I knew from my student days. Imagine my surprise when he told me that his wife (20 years older than me) also had otosclerosis. He told me not to worry because it was operable. His wife had recently had successful surgery in Melbourne.

I accepted his offer to work as his Research Assistant, and went to Melbourne to see Dr Rory Willis. I was in fact double lucky. Career wise and hearing wise. And I have been forever grateful.

Dr Rory Willis was a very skilled surgeon specialising in stapedectomy surgery. This was very new micro-surgery in the 1960s. It replaced the tiny (calcified and malfunctioning) bones in the middle ear with a prosthetic stapes.

Dr Willis is still acknowledged for the outstanding results he achieved 60 years ago.

I first saw Dr Willis in 1964. He explained everything about otosclerosis and the surgery. I had to wait four more years for him to operate, which he explained was to allow the overgrown bone to reach a certain 'stability'.

He operated on my left ear in 1968 when I was 24 and it was wonderful to hear well again. I didn't need to wear a hearing aid, and I stopped going to lip-reading classes.

He 'fixed' my right ear in 1977, at age 33

Dr Willis advised me to ALWAYS avoid loud noise, and to never deep-water dive.

He also explained that, because I had early-onset severe otosclerosis, I should expect some 'further hearing issues' later in life ... "in my 50s".

I filed that away in my 'sometime later' file.

1997- 2020 (Stage 3 of my hearing loss journey) Aged 53 to 76

The tiny implanted prostheses are still working perfectly. My hearing was 'normal' for many years. However, that 'sometime later' did arrive, and I became gradually aware that I was again 'hearing impaired'.

I started wearing hearing aids again (in both ears) in 1997 at age 53.

It was at this time that I joined Better Hearing Australia ... and attended their lip-reading/hearing awareness classes

This secondary deafness was progressive and with hindsight, I realise that these classes offered me hearing-loss counselling, providing support and understanding at a time when I was dealing with losing hearing for a second time. Until attending classes I had no knowledge about other causes of hearing loss.

I realised that many were dealing with situations so much more challenging than my own.

And I learnt about Assistive Listening Devices which helped me feel more positive about my future hearing loss.

The BHA volunteers are, along with the Professor and Dr Willis, my hearing-loss heroes. After a few years I dropped out of classes, but have maintained my membership. I am so much better informed because of BHA, and whilst I hope I never have to rely totally on lip-reading, if I can see the speaker's face ... I can hear.

I have managed well with hearing aids, upgrading every 7-8 years.

Last year I upgraded my hearing aids from 2012 technology to 2020 technology and, whilst expecting to hear much better, found that there was not much improvement.

I saw Dr Nigel Biggs*, a Sydney ear specialist considered an authority on otosclerosis, and looking at the CT scan of my ears, he pointed out the spread of otosclerosis calcification into my cochlea. With 'nerve' loss over more frequencies, hearing aids are now not as helpful as before. However, a cochlea implant will help when needed.

A note in conclusion

I would be particularly interested to hear from anyone who had successful stapedectomy surgery in the 1960s & 1970s, and who, because of the early onset of otosclerosis, now have cochlea hearing loss.

[With later onset otosclerosis, the cochlea is less likely to be affected, and hearing restored by successful stapedectomy surgery is on-going.]

My otosclerosis hearing loss pattern differs from those with failed stapedectomies (like my sister).

[Unfortunately, many of these early stapedectomies were not successful. It was new surgery and different surgeons had different outcomes.]

Others (like my cousins) have managed their later onset otosclerosis with hearing aids ... without surgery.

I would be pleased if sharing my experience is helpful to others who (like myself) are fortunate to have had successful stapedectomies in the 1960s & 1970s. By definition this cohort will now be senior citizens.

If you have a successful stapedectomy done in the 1960s and 1970s ... MRIs should be avoided.

I was warned of this a few years ago and Dr Biggs has confirmed that there is always a question mark over the type of metal used in those early prosthesis implants. It is risky to have an MRI because if the metal is magnetic the prosthesis can be dislodged. After such a long success, how terrible this would be. (Later surgeries are MRI compatible.)

Going forwards

Recent research suggests that whilst genetics predisposes some to otosclerosis, the disease is activated by the measles virus.

With measles now prevented by vaccination, otosclerosis may become very uncommon.

In my close family, myself, my sister and my daughter* (who follows my pattern exactly) all had measles naturally. My two granddaughters (currently aged 16 and 12) are vaccinated against measles, and so far, have perfect hearing. Fingers crossed.

*Dr Biggs did the second of my daughter's two successful stapedectomies. The first was done by Dr Tonkin. Her otosclerosis follows the exact pattern as mine with early onset and stapedectomies to both ears 9 years apart. Now aged 48 she has entered the cochlea stage and has just started wearing hearing aids (again).