



The Biopsy Bugle

Winter 2017

**The Australian Heart
Lung Transplants
Association Inc.**

Since 1983

President's Message



It is with great sadness that I begin this edition with the unfortunate news of the death of two prominent members and contributors to AHLTA . Peter Wicks and Don Pill both passed

away in July . Peter was the President of the AHLTA Committee for several years when I first joined the Committee in 2009. Don Pill was active member of the Committee at the same time. Both men were very generous with their time for AHLTA and helped the development of the organisation in a significant manner. They will be greatly missed . On behalf of AHLTA , I would like to express our condolences to the families and friends of Peter and Don. Please see tributes contained in this edition.

On a much happier note, we had our Thanksgiving Service and lunch in early June which was well attended . At that time the Doll Ladies presented AHLTA with its annual contribution which this year was \$20 000. I would like to acknowledge the significant contribution made by these wonderful people over many, many years. Their tireless commitment to raising funds to support our organisation is beyond

compare and so very much appreciated. I should point out that their annual contribution is earmarked for the Financial Assistance Program which provides one off grants to people either on the waiting list for a transplant or who have had a transplant. As we all know, these can be very challenging times financially and this program allows us to ease that burden in a small way. AHLTA thanks you Doll Ladies for your continued support that allows us to keep this important program going.

The work on the updating the Constitution and the creation of a Board of Directors for the organisation continues. The Committee is meeting in July to discuss this as well the organisational strategic direction. Updates on progress will be provided in the next edition.

I would like to acknowledge the many people who have contributed to the organisation this year, both in volunteering their time and through making donations. I thank you for this as your support is vital to the success of AHLTA Please feel free to contact me directly should you wish to become involved in any way or should have an interest in the work in which the Committee is engaged.

Regards
Regina McNamara

In Memory of Peter Wicks

Peter was a man of great humour, generosity and integrity whose philosophy of life was "Just Get Over It And Get On With It" - which was the title of a memoir he had begun to write, and sadly at the time of his death remained unfinished.

Peter was given two new chances at life when, after massive heart damage at the age of 39 in 1993, ultimately necessitated a heart transplant. After a long wait due to his rare blood type, and a number of false alarms, - this life-saving 'miracle' occurred on 14th December, 2001. At this time, he also became a donor, giving the healthy valve of his original heart to a very young man who subsequently married and had four children and forever remains deeply grateful..

With great determination Peter eventually returned to full-time work until problems developed with his new heart which ultimately saw him hospitalised for long periods before he was persuaded to place back on the transplant list. He was very reluctant to do this as he felt he was being selfish when others died waiting for a 1st transplant. The amazing transplantation team of St Vincent's Hospital in Sydney encouraged him by saying his rare

blood group worked in his favour in this case, as a heart could go to waste if there was no one of that type waiting.

This second transplant occurred on 19th July, 2007 – but not without incident. He remained in a medically induced coma for 3 months after the operation having had several strokes. This didn't stop the unwavering Peter who was determined to attend the weddings of his eldest son in Gundagai in late November 2007; and his eldest daughter on the Gold Coast 2 weeks later, when he managed to walk her down the aisle – without even using a stick! What resilience!

Once again he eventually returned to full time work, saying he must pay full tribute to the amazing generosity of the donors and their families who had got him to that point. And since that time, all six of his children married and gave him 8 beautiful grandchildren – a great joy! The years following his 2nd transplant ensured he was able to achieve some goals, and strike some dreams from the 'Bucket List'- especially seeing animals in the wild on a trip to Africa where his photography skills were well showcased.

During this time Peter became an active member of the Australian Heart/Lung Transplants Association (AHLTA), eventually taking over the position of President for a number of years. As always his involvement was whole-hearted as he regularly drove to Sydney for meetings and activities and then returned home to Canberra the same day. It was only further health issues that caused his resignation.



Not to be deterred in his quest to show his eternal gratitude and honour to his donors, he set up a Facebook page, (now called Heart/Lung Transplants Australia, as he felt it needed to be separated from AHLTA in case people thought it was solely for members of the Association). He did this to give recipients, their families and donors a place to share experiences, concerns, gratitude and issues, with a strict guideline to ensure that no one gave unqualified medical advice. He thought he may get 20 or so members – however the need he addressed was great and at last count the membership had reached over 1 600 worldwide. What a significant legacy!

His was a well-balanced life of hard work and variety of activities. He was at various stages and in no particular order, a qualified electrician; photographer; policeman; security guard; hotel manager; manager of security for Wormalds in Papua New Guinea; taxi driver; tow truck business proprietor and operator; volunteer for Volunteering ACT, then its IT specialist, and Finance Manager; adult trainer; hospitality worker; computer systems salesman and installer. In other words, he was unafraid of change, hard work and always a diligent worker and staff member prepared

to work every hour he was needed plus more - often without recompense.

Life was not all work though. He was very much a water person and excelled at swimming, and loved water skiing, boating, fishing, and camping; while his following of the Bathurst car races and particularly Peter Brock, was almost fanatical and to be interrupted at peril!

He was the king of gadgets! He was continually looking at the latest advances in computer and information technology of various types, and also in cameras. He was an artist and perfectionist in photography

and patiently waited to find the perfect composition of a shot – often taking myriads of pictures to ensure he had the almost perfect one – though never admitting to being totally satisfied! Very late nights, early starts, icy cold, searing heat – none of this was of consequence when the aim was the perfect picture.

Peter loved animals and particularly the dogs that had been part of his life for so many years. He had a special affection most recently, for his malamutes Kodi and Rusti. He took special pride in training Kodi for dog-sled racing in Kowen Forest. It was such a disappointment to him when his declining health prevented him from continuing this activity.

Sadly the final few years of his life were to be blighted by ongoing health problems, several more strokes and rehabilitation regimes, medical files that medical staff were heard to say needed a pantechnicon to move them, and a list of medical conditions that encompassed many pages of the medical dictionary!

Peter also freely gave of his time, even when in hospital, to talk to the many medical students who were interested in his case, and was often the diagnostic Case Study for doctors' exams. He saw it as a way to try to express his gratitude to all the wonderful people who had seen him

through so many medical crises. It frustrated him immensely that he was unable to adequately express his deep gratitude to all those involved in his care over such a long time, particularly during his extended stays in St Vincent's in Sydney, Calvary Hospital, Canberra, then eventually Clare Holland Hospice in Canberra. One day he made a list of all those who he wanted to thank for their very significant part in his life, however due to his strokes his memory for names had declined. So on his behalf:

Peter was deeply grateful to the amazing medical teams from St Vincent's Hospital, Sydney, and Calvary Hospital in Canberra, who have so wonderfully supported him through his transplant journey. This includes his GPs, Surgeons, Cardiologists, Neurologists, Nephrologists, Endocrinologists, Pharmacists, Social Workers, Pastoral Carers and all ancillary staff: so many of whom were to become his life-long friends.

Sincere thanks too to the wonderful gentle and caring staff of Clare Holland House, whose Hospice care enabled Peter to live out his final days (with the wry humour that was so indicative of the man) in a relaxed, peaceful and loving atmosphere.

Lorraine Higgins
Friend of AHLTA

In Memory of Don Pill

We were very lucky to have known the wonderful Don Pill, heart transplant recipient and all round good man.

Don was given the gift of life 19 ½ years ago after a major heart attack. He made the very best of these extra years, spending time with his family, fishing, boating and supporting his mighty South Sydney!

Don was a dedicated family man. He and his wife Diane have two children and 5 grandchildren. The grandchildren affectionately call him "Poppa Pill" which Don found amusing as he had to take a lot of pills! He had a wonderful, quirky sense of humour and was always making you smile.

Don was a wonderful friend to AHLTA. He was Vice President, committee member and a great supporter of the Association's activities. He made a significant contribution to the association, especially using his expertise in IT and computers to assist with the computer set up and maintenance at AHLTA house. He also supported his wife, Diane, who works tirelessly with the Doll Ladies

to raise money for AHLTA.

Don made some wonderful friends with other transplant recipients and has maintained contact with them for many years. He was supportive and encouraging to new recipients. I remember him giving me good advice and encouragement early on in my transplant journey which was very comforting. He was always willing to lend a hand.

Over the past few years Don has battled many health issues but he always kept a positive attitude and had a smile on his face.

Goodbye Don. Thanks for everything. We will miss you.

Lyn Kerslake
Vice President of AHLTA



Poem from one of members

Little White Pills

Little white pills that keep you alive,
prevent you from rejecting new lungs.
Little white pills that pack a punch;
horrible pills called Prednisolone...

Walking this transplant road,
holding your head up high;
Suffering the side effects
of this tiny pill of white...

Initially, doses are very high,
and combined with other drugs...
Hallucinations, visions and nightmares
are how the side effects start...

Doses significantly reduced in a month
but side effects you'll always find.
The effects can be instant in some,
in others it just takes time...

'Pred' head or 'Pred' face,
one of the earliest signs...
Your face swells up, chubby cheeks
for the first time in your life...

A hunger which will put to shame
any teenage boy you'll meet...
Midnight snacks take on new meaning
when the Prednisolone munchies hit...

A bloated belly I call 'Pred'nant,
feeling like you weigh a tonne;
Something else we'll all encounter
on this journey just begun...

Emotionally affected in so many ways;
Mood swings the most common...
Surely all these side effects
set this emotional roller coaster to action...

Side effects may be instant
but there are many long term ones...
The things we have to deal with
when we get new lungs...

Although side effects aren't pleasant,
the alternative is much worse...
We may all hate Prednisolone,
but being alive proves it's worth...

Leanne Demers, 21st June, 2013



Asthma breakthrough: Antibiotic used to treat lung disease can reduce attacks, study finds.

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The research team from the Hunter Medical Research Institute (HMRI) in New South Wales gave the drug azithromycin to 200 patients whose asthma could not be fully controlled with traditional medication.

After taking the antibiotic three times a week for nearly a year, the patients reported a 40 per cent reduction in moderate and severe asthma attacks.

“Many of them were surprised by the benefit. One lady told me she'd never felt this good before, and she'd had asthma for many, many years,” study author Professor Peter Gibson said. Azithromycin is an antibiotic with anti-inflammatory properties that was hailed as a miracle cure in the 1980s for the lung disease diffuse panbronchiolitis.

“It's a very rare disease that kills people. It's rare in Australia but is quite common in Japan,” Professor Gibson said.

“They discovered in the 1980s that if you treat these patients with azithromycin, they live. The patient had to take it for a year, but it kills the disease.”

HMRI has found the drug also reduces swelling in the lungs of asthma sufferers.

“The main problem in asthma is narrowing of the airways, and that's caused by muscle spasms and inflammation. Azithromycin appears to work on the swelling and the mucus part of the problem,” Professor Gibson said.

'I feel confident to do almost anything now'

Margaret Widders was initially sceptical when her doctor signed her up to the trial of azithromycin.

The retired school teacher from Sydney has suffered from asthma since childhood, but in recent years she'd developed a persistent hacking cough that made exercise impossible.

"It was horrible to hear whenever I exerted myself, I would be coughing and it did restrict me. I had to sleep with a few pillows to reduce the coughing at night," she said.



After taking azithromycin for about a year, Mrs Widders' cough disappeared.

She no longer needs to take the antibiotic and has halved her traditional doses of asthma medication.

"I'm just so much more active. I walk up to 10 kilometres a day — quite challenging walks sometimes — and I feel fine," she said.

"I think it has improved me to that stage where I feel confident to do almost anything now."

Antibiotic resistance the next challenge for researchers

The HMRI team is now working on ways to prevent antibiotic resistance in patients who take azithromycin.

“It can be done. We must be selective about the people for whom the treatment is given, and also monitor the potential side effects of the treatment,” Professor Gibson said.

“We think there could be opportunity to develop different ways to give this antibiotic, for example, in shorter periods. Perhaps having a drug holiday, giving it in even lower doses.”

Professor Gibson is also working with his team on an inhaled version of the drug, which would remove the antibiotic but still deliver the anti-inflammatory to the patient's lungs.

The study has been published in the UK's Lancet Medical Journal.

Source: ABC News
May 2017

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AHLTA STALL DATES IN 2017:

22 August 2017

21 November 2017

AGM and Christmas Party: 3 December 2017

Stay tuned for details

We are always looking for volunteers at our stalls so if you're able to spare some time on these Tuesdays, we would love to see you there.

Donation Slip

Please help support AHLTA by making a donation!

Donate now

Your donation will make a difference to AHLTA' current and future services for heart and lung patients, their families and carers. In return for your generous contribution, AHLTA will guarantee that your donation is applied to provide service to members in need.

All donations of \$2 and over are tax deductible.
CFN: 14158 ABN: 30 752 596 540.

YES, I would like to make a donation to AHLTA.

Your support will provide:

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- \$100

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month quarter six months year.

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