



THE AUSTRALIAN HEART/LUNG TRANSPLANTS ASSOCIATION Inc

# **The Biopsy Bugle**

**Spring 2018**

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

**Since 1983**



## President's Message



As we approach the end of another financial year for AHLTA and another AGM in December, I cannot help but notice how quickly this year has slipped by. The focus of the year has

been undoubtedly on membership engagement with several committee members working strenuously to update our membership records as we prepare to launch a new engagement platform. It was, and is, a monumental task, one which has not been attempted in the organisation for many years. I am happy to report that we are almost there and soon we will be in a position to commence with a new platform with the objective of better communication with AHLTA members and enhancement of the way we obtain feedback.

As you may be aware our Annual General Meeting will be held on December 9 ( details in this edition). I would like to encourage any of you who have the time and interest to consider joining the AHLTA Committee in some capacity. AHLTA relies for the most part on the contributions of volunteers in order to achieve organisational objectives. There are a multitude of tasks to be accomplished and we would very much appreciate your help. Available positions and

responsibilities are included in this edition . Should you have an interest in contributing to the work we do, please contact me directly by email or mobile ( outlined below) and I can discuss this directly with you.

At this time I would like to inform you that it is my intention to step down as President at the AGM on December 9 and resign from the Committee as well at that time. It has been a privilege to work with such a dedicated group that have volunteered on the Committee over the last 9-10 years and I certainly applaud the commitment of the current and past members. However, through a combination of my own health issues and the demands of my current employment, I do not feel I am in a position to serve the Committee effectively at this point. When volunteering my time I want to give it everything I have and I am just not in a position to do so right now. I have enjoyed immensely my work with AHLTA over the years. I believe the organisation has a great many achievements to be proud of. I wish the Committee and the membership all the best in its future endeavours and particularly with engagement as outlined above. I will be available to help in any way the Committee feels appropriate in the future with respect to small projects or anything else.

Jerry McNamara  
President  
ceo@participateaustralia.com.au  
0411 400 307

## SOCIAL EVENTS and those “TAKE YOUR HEART AND LUNGS OUT” posters...

During the database phone-a-thon where we spoke to quite a few AHLTA members, many people indicated that they felt isolated because of the never ending rounds of doctors visits, hospital and illness, and others indicated that they were looking for more social events to be run by AHLTA. The first step in helping AHLTA members to improve their quality of life is to get people in contact with others, and to get out of the house when they can. Therefore, we are now asking people if they want to be advised of social opportunities, and the next stage of this is to find out what social opportunities people want to go to. As an interim measure, you may have seen in the posters in the Heart Lung Clinic, or on our website, regarding day trip opportunities. (The Take your Heart and Lungs Out Poster).

These are opportunities for those who are stuck in Sydney post-transplant, and any others who want to go somewhere on a day when the weather is fine, and go somewhere a bit different for a few hours. These trips are currently sourced from Eventfinda, What's On guides for Sydney, Newcastle, the Central Coast,

Wollongong, and the Blue Mountains, to keep trips within easy distance of St Vincent's, and the public transport system. Also, although the posters on the wall at St Vincent's are bare of details about how to get to events and activities, we are checking to find nearest bus stops and putting public transport access details on the website and our Facebook page, although many events listed on Eventfinda do give this information. However, these methods of finding interesting things to do are not infallible, and there are other events that are hosted that we don't hear about until its too late. (Secondly, although we tried, there weren't many events listed for Wollongong....)

Also, we have people all over the state, and if you know of an event happening near you, please contact us so that we build up a better portfolio of activities and events that may appeal to other people in your area wishing to have a day out. As far as Social Events go, we also need more input from you as to what events you would like to attend, and how much you are willing to pay, (and how far you are willing to travel,) for an AHLTA

event. Some of the suggestions we have at the moment are to

- arrange a cruise on Sydney Harbour,
- join one of the steam train tours,
- pick a park on the Parramatta River and arrange for food vans to cater for the event,
- take the AHLTA banner to Food and Wine Festivals, as these have lots of

catering on hand..

Once we get a better idea of what you want to attend, we can sort the membership database to contact those who have expressed an interest in any given event, and let them know if other AHLTA members are likely to attend. This

may be very helpful for those of you who live in country areas, as we can advise of events that service a cluster of members within a reasonable travelling distance for you. Hopefully, we will end up with an Annual calendar of events, so that you can quickly check if anything you enjoy doing is coming up in the next few weeks. Please ring or text Lea on 0414 516 412, or email Andy or Joy on [andyjoy@optusnet.com.au](mailto:andyjoy@optusnet.com.au) to give us your thoughts on potential activities, and your preferences for events that you would like to attend.

## AHLTA Membership Database Update

A few of us have been working for several months to ensure that the details we have for all our members are as accurate and complete as possible.

As part of this process, we have spoken to many of our members and now have a better idea of what information we should be adding to our members database so that we can provide more opportunities to help out members in the future.

We are trying to get as many email addresses as possible, to

allow the Biopsy Bugle to be delivered electronically to those who are happy to receive it that way, and to allow us to send emails to members to advise of upcoming events or provide information. If you don't have an email address, we would like your mobile phone no, as we can send bulk mail via SMS. Also, as many members have indicated that they would like to have more events and activities where they can socialise with other AHLTA members, we are adding some

new fields to the database. We are now noting if you are a member who would like to go to social activities, and which sort of activities or events are your preferred choice.. We are also adding a volunteer field, so that we can identify which members would like to help when we have AHLTA events, and the tasks they are happy to do. Please contact Andy Gough on 0418 466 095 or Lea Marheine on 0414 516 412. Or email [andyjoy@optusnet.com.au](mailto:andyjoy@optusnet.com.au) if you are interested ensuring that your information is in the database. As many of our transplantees and their families do not go back to full-time employment, we are also interested in compiling what skills and activities that you would like to make available to AHLTA, so that we can sort through our database to find people who may have the skills we need for some of the projects we are working on, or may initiate at some time in the future. A conversation at a recent Committee meeting identified skills in Marketing, Networking, Fund raising, Event Management and Social Media as critical to some of the projects that are being pursued by the current committee. It is also worth noting that for many years, the AHLTA committee has performed with a bare minimum of committee members, and would welcome new trans-

plantees/carers or people who are willing to take on tasks to assist the Committee, even if they are not prepared to attend committee meetings. Also, there is no barrier to those who are not Sydney residents to becoming members of the Committee. Technology allows us to have meetings even when Committee members are too ill to attend the meeting in person, or are travelling (or resident) too far way to travel. It would be wonderful if those who live more than an hour or so away from Sydney could contribute more of their experiences as country transplantees and family members to the decision making process at the Committee level. Even if you don't attend the AGM on 9 December, you can still nominate as a Committee member. Please advise Lisa Slater on 0439 598 205 if you would like to join the Committee.

## AHLTA Market Stall

Tuesday, 28 August.

We had laden tables, lots of yummy slices made by Libby and Sue, including coconut ice, (it all went), jaffa cookies, cherry slice, date and lemon slice and a fig cheesecake to die for.

All of these were beautifully wrapped and ideal as gifts.

Stephano and Trish also contributed some more cheesecake to boost our stocks as the other goodies ran out.

Winifred and the doll ladies, Diane and others, supplied an array of Jams, Marmalades, Preserves, Chutneys and Lemon and Strawberry Curd, Roi turned up with an array of baby dolls with hand knitted layettes, bootie and bonnet sets, crocheted rugs, and bedsocks specially knitted for patients in the Hospital who get cold feet. Stephano and Trish also brought home made pasta boxes, ready for people to take home and cook. And yes, they were divine!

Lyn brought the usual AHLTA merchandise, and we saw quite a few car stickers, shirts, and mugs walk out the door.

Our only problem was that there was no EFT machine available..... However, it was a very good day! Next stall is Tuesday, November

27, in the Foyer of St Vincents Public. Please contact Lyn on 0403 334 048 if you have anything you would like to contribute to this stall.

Quick tip! If you turn up to buy some jams at the next Market Day – Lemon Butter goes first, then the chutneys, then the berry jams!

For those of you who wish to



contribute preserves and jams for future stalls, lemon butter, lime marmalade and chutneys are sure fire sellers! Also remember that this stall is probably a good opportunity to sell items suitable for

Christmas Gifts. Please contact Lyn Kerslake on 0403 344 048 if you have times that you would like to include in the next stall.

## One experience from the other side

**Organ donor families are often left in the dark. With the permission of the mother Jean, I submit the following excerpts from her post:**

“Our gorgeous son Richard suddenly passed away in Canberra Hospital March 2018. It has been the most devastating time in our lives since that sad sad day that we had to accept the fact that our ‘golden boy’ wouldn’t survive but the best outcome from our tragic loss of our gorgeous son is that he brought life to four recipients that have been blessed with Richard’s ‘gift of life’.

We told them (Donate Life) that we wanted it noted on Richards file that we would like to be kept up-to-date regarding the recipients and their health situations. We were assured that we would be kept informed”.

This did not happen. She writes “Why make promises to the donors families and then not carry them through?” It is not easy to write to your donor family. It took Andy over a year but it was so worthwhile. We now know that a member of the family has been invited to take part in the Review of the Organ

Donation Retrieval and Transplant System by Ernst and Young 2018. They were seeking both Donor families and recipients to interview.

Andy submitted his offer to participate but was not accepted which was very disappointing. Nonetheless it will be interesting to see the results when published. Please write to your donor family when you can. It makes a world of difference to them.

Addit: since writing this I have heard from Jean that a recipient of his liver has contacted her thanking her for a healthier life with his family, and she writes in response:

“I’ve assured Mark that we’re so grateful to him for managing to find us, it’s a dream come true for our families and we all plan on meeting each other soon”.



# GET INVOLVED!

Everyone's invited, recipients and carers, to our Christmas Lunch following a short AGM on December 9th. All the Committee positions will be declared vacant. Nominations will be accepted from the floor.

With Jerry leaving us we are looking for members to join the enthusiastic team with Lyn Kerlake, Lisa Slater, Andy Gough, Libby Maher our transplant recipients, and others who support them including Babak our magazine editor, Susan our Treasurer, and Associate members Lea Marheine and Joy Gough.

Nominations have been received for the position of President along with the continued service of a Vice President and Secretary. This team is looking forward to having new members join them.

So whether you are a transplant recipient or carer please join us on this exciting and enthusiast committee taking us on the journey of a new member platform and better engagement with you all.

You're also invited to our Christmas lunch, invitation with directions enclosed, for your frig door.

## VALE SAM CHISOLM

Sam Chisholm, who died on Monday evening the 9th July aged 78, leaves an enormous gap in a powerful industry but was always renowned as the point man and a great mentor.

He was at times the managing director of TCN Channel 9 Sydney, the head of BSkyB and a board member of Rupert Murdoch's News Corp.

However Sam's health issues made travelling and the demands of an international position harder and harder to manage. In 1997 he stepped aside. He returned to Australia and was appointed chairman of Foxtel.

Sam suffered from emphysema, and he became more and more dependent on treatment. He never moderated his lifestyle or reduced his work rate but finally had a double lung transplant in 2003 and had 15 years' service from his



new lungs, a remarkable return.

Sam's life was also blessed by a beautiful head of network PR, Sue Ward, who worked closely with

him for over 30 years and whom he married in 2002. The tranquillity they achieved at their farm Bundarbo led to contented years.

Following his double lung transplant in 2003 we believe he was active in the AHLTA. His main legacy however was his establishment of the David Hookes Foundation which led to an increase in the

number of donors registered in Australia.

We acknowledge Sam's accomplishments as a leader of the Organ and Tissue Authority Advisory Council & his appointment as an Officer of the Order of Australia. He was a Director and Life Governor of the Victor Chang Cardiac Research Institute.

With acknowledgement to Bruce McWilliam & THE AUSTRALIAN and to Mrs Sue Chisolm for her assistance with this article.

## A big thank you to our generous donors

The Association wishes to acknowledge the donations from everyone who has helped our work to assist Transplant recipients and their families this year and in some cases, for many years.

It's always difficult to single out any particular bodies however it would be unkind & thoughtless not to mention longtime members Karen Kennedy of Gunnedah Apartments, Carmel McKay of McKay Property and Finance and Helen Ogle of WHO Printing.

# THANK YOU!

Then there are the groups: The workers on the foyer stalls, who, besides waving the flag and earning some dollars, have an inordinate amount of fun!

Then our thanks to all our individual donors and people who contribute through Everyday Hero.

Last but not least a special thanks to the team known as "The Doll Ladies" who work extremely hard every year, led by the ever enthusiastic Winifred Garland. They make all their own jams, cakes and handcrafts, then sell them at stalls from Manly up to Gosford.

Thanks everyone, we really DO appreciate your efforts!



Please rsvp by  
**Saturday 1 December 2018** to  
Lslater6@gmail.com  
0439 598 205 (Lisa Slater) or  
0415 226 316 (Joy Gough)

Plenty parking available, and it's also very close to public transport. Please let us know if you have any dietary requirements.

We look forward to seeing you then!



### **AHLTA Annual General Meeting and Christmas Party**

**The President and Committee of AHLTA cordially invite you to attend**

#### **the Annual General Meeting and Christmas Party**

**to be held at 11.30AM (please arrive by 11.20AM)  
on Sunday, 9 December 2018  
at Canterbury League Club  
28 Bridge Rd, Belmore NSW 2192**

Following the brief AGM formalities, attendees are invited to enjoy complimentary lunch and drinks.

## Health NEWS

Peter Macdonald, heart transplant pioneer, helping close the Indigenous life-expectancy gap

Every six weeks or so he flies out to the Condobolin Aboriginal Medical Centre, in central-western New South Wales, to look after the health needs of the locals.

Centre manager Katie Worthington said Professor Macdonald had been coming since 2006.

"We have this long-standing joke with Peter that he's the longest-standing doctor in rural Condobolin because, you know, doctors come and go, but Peter's been coming for over 10 years," she told 7.30.

It all began 12 years ago, when an Aboriginal patient and his wife told Professor Macdonald about the lack of medical services in Condobolin.

"She was the one who approached me and said there's basically nothing out at Condobolin, certainly no specialist services, and would I be prepared to come out and do a clinic there," Professor Macdonald said.



"I said, 'Yeah, it'd be a nice change to working in the big city hospital on a daily basis'.

"So I flew out for the first time in December 2006."

Anna Dargin was one of Professor Macdonald's first patients and she still sees him regularly.

"We need someone to come in like this here, to do all the things, the treatment here rather than having to go away," she told 7.30 report.

"It was a real treat seeing him today."

Professor Macdonald said: "I'm seeing patients that I've seen many years in the past and it's good to see them come back.

"And you can see the benefits in their health over the long term."

# AHLTA

## Merchandise Price List

♥ Shirts	\$30
♥ Drink Bottles	\$5
♥ Umbrellas	\$25
♥ Mugs	\$10
♥ Car Stickers	\$10
♥ Hats	\$15
♥ Pens	\$2

If you wish to buy AHLTA merchandise,  
it will be available at the Market Stall at St Vincent's on 27 November,  
or you can contact Lyn on 0403 344 048.

# Donation Slip

Please help support AHLTA by making a donation!

Donate now

Your donation will make a difference to AHLTA's 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:

- \$25
- \$50
- \$75
- \$100

I would prefer to give a regular gift of \$ \_\_\_\_\_ To be automatically charged to my credit card every:

month  quarter  six months  year.

### Donation Payment Details:

- I enclose a cheque / money order payable to AHLTA Inc.
- Please debit my credit card.  VISA  Mastercard

Card No.

Expiry Date   •   Cardholder's Name \_\_\_\_\_

Cardholder's Signature \_\_\_\_\_

Email \_\_\_\_\_

Please help us to save on future expenses by providing your email address.



Website: [ahlta.com.au](http://ahlta.com.au)  
Email: [Lslater6@gmail.com](mailto:Lslater6@gmail.com)  
Phone: 0439 598 205  
Postal Address: PO Box 309  
Kings Cross NSW 1340