



The Biopsy Bugle

Spring 2016

The Australian Heart
Lung Transplants
Association Inc.

Since 1983

President's Message



Hello everyone,
I would like to let you know that at a Committee meeting held in July of this year, I assumed the role of President

. For personal reasons, Kimberley Livingstone has had to step down from the role although she remains active on the Committee. Kim has dedicated considerable effort to the role over the past many years and I know that you will join me in thanking her for that commitment . This will be acknowledged more comprehensively at the upcoming AGM/ Christmas Party wherein all positions will be up for election once more. I encourage you to become involved in the Committee and enhance the direction of the organisation as we move forward.

Having served as the Treasurer of AHLTA for the past 7 years , I can attest to the financial sustainability of the

organisation which allows us to continue the work that we do. While stable , nevertheless , we must continue with our fundraising efforts and I would like to acknowledge and thank all the people and organisations that continue to support our efforts through much appreciated donations.

Most importantly , I would like to hear from all the Members and Associates on matters that are most critical to you. AHLTA has developed a brief survey to assess feedback from you and this is enclosed .

Your participation in this survey would be immensely appreciated as we strive to enhance our involvement with the membership and identify and prioritize the work that we do. If you have any questions or issues please do not hesitate to contact me directly on 0411400307 or by email on ceo@frans.com.au.

Regards

Jerry McNamara
President

A great achievement for our volunteers

The wonderful Work of the Doll Ladies was recently recognised at the Sydney City East regional ceremony of the NSW Volunteer of the year.

The NSW Volunteer of the Year Awards is an annual program run by The Centre for Volunteering to recognise the outstanding work of volunteers in every region across NSW. Twenty award ceremonies are held across NSW from August to October where nominees are recognised with certificates and winners announced.

The Minister responsible for volunteering, John Ajaka, said the awards are an important way of recognising the vibrant contribution individual volunteers make towards strengthening communities across NSW.

It was a lovely afternoon and although the ladies did not win their team category we are very, very proud of them all and thank them for all the work they do for AHLTA.



Another successful Bunning's BBQ

AHLTA held another very successful Bunnings Day on 13 of August on a nice and sunny day in Belrose NSW.

There were lots of sausages, onions and bread to be served to many hungry customers as well as the fabulous jams and pickles made by the Doll Ladies. As usual, we started from 8AM and finished around 3PM. Some of our members managed to come along and

help us with serving customers during the day.

Thank you to all the wonderful helpers on the day who helped to make the day such a success! We made well over \$1,500 on the day!

We look forward to our next Bunning's BBQ in 2017 and would love to hear from you if you are interested in helping out on the day.



Story of my journey

Imagine being a non-smoker and healthy being told that you had a rare deadly lung disease and eventually to live you would need a transplant. Pretty shocking to myself and to my family hearing that. Hi – my name is Tracey, I am 49 years old and I have had a double lung transplant at Prince Charles Hospital in March 2014.

After being misdiagnosed for asthma, in June 2012 I was told I had IPF – idiopathic pulmonary fibrosis – there is no known cause, no cure and the only effective treatment is a transplant.

I maintained this disease for about 18 months with medication before I started to rapidly decline in December 2013.

By the time I was transferred to the tx team at Prince Charles Hospital – I was in a wheelchair, I couldn't walk up stairs, I couldn't shower myself, I found eating was even difficult when you can't breathe, I was hooked up to oxygen 24/7, so everyday

I would just sit in my lounge room and pretty much do



nothing. I went from being a very independent person to totally relying on my family for everything – I hated it so much which caused great depression – my family had to witness me slowly deteriorating.

I met Dr Peter Hopkins the Director of the tx team in February 2014 at Prince Charles Hospital who plays a very important role in my life as does the rest of the tx team – after meeting with him he shook his head and

said "Trace we have three months to assess you and find you an organ – your disease is at the end stage." So an appointment was made quite quickly for me to be assessed for tx.

Luckily for me all of my tests were clear and I was placed on the tx waiting list. Dr Peter then told me he would prefer me living in Brisbane to better my chances to receive an organ – it broke my heart to leave my home, my kids, my friends behind to move to begin the wait. Saying goodbye to my children at the airport not knowing what was ahead was one of the hardest things I ever had to go through.

The waiting for a donor was a scary time for time, the night before I received the call I said to my husband Greg "I've had enough of being ill I just want to die this isn't living" – the morning after feeling so depressed - I was blessed because after only waiting 15 days I received my one and only call.

My call come in about 8.00am in the morning and I was being wheeled into

surgery about 4.30 that afternoon after being told that my donor was a match. It was a Thursday and I woke up in ICU to see my family on Saturday morning – the best sight ever. The feeling was amazing – I could breathe without effort. Of course there was a lot of pain afterwards, I found it got better as I recovered. I even went for my first walk around the ward – of course I had a huge entourage of medical people, tubes running everywhere but I was out of bed and walking two days after such a huge procedure. On the Monday I was transferred to a special tx ward when the hard work really began.

I was discharged and walking out with new lungs and a new lease on life 15 days later. I felt so honoured, privileged and so blessed to have new lungs that had belonged to someone else. I remained in Brisbane until May, when I finally heard those wonderful words from my tx doctor – Tracey you can go home.

Of course I have suffered side effects from the medication – I have experienced weight

gain, puffiness, headaches, mood swings, tremors, forever hungry and hair loss but a small price to pay for a second chance of life.

I've had a few hiccups along the way – two rejection episodes which were quickly picked up and treated and

I respect the confidentiality process that is in place by donatelife because not everyone wants to be found – the process is in place for a reason – that's to protect peoples privacy. However I have been blessed to have been found by my donor family through social media



I was put in hospital after catching a common child's cold which resulted in severe pneumonia for me. Apart from that I'm quite healthy and lead a very normal life. I walk every morning, I can drive a car, I'm back at work, and I'm back in charge of my household calling all the shots as a mum usually does – my family wouldn't have it any other way!

– they used hints that were permissible in my letters to find me – it took them 90mins to find me on the internet. I will never forget that day on the 15th May 2015 when I received their call.

Since knowing my donor family – the relationship between the two families is amazing – I have been welcomed into her family as one of their own. I have

met my donor parents, her daughters and majority of her siblings. There were no awkward moments any time – there is always much love and laughter when we are all together. My donor is Aileen, a young mum of two daughters who loved life, her children and was adored by those who knew her.

Its now been over two years since my tx – I don't have any regrets – of course I felt guilt because someone died to save me – but after talking to my donor family – they have reassured me – they don't regret going through with the donation – they get comfort knowing they fulfilled her wishes and that people like me have been saved by her beautiful gift of life. While tx is considered to be a treatment and not a cure, I am so thankful for my second chance of life.

I make the most of what I have been given – I don't take things for granted – my family mean the world to me and have been the best support that a mum and wife could ask for – never ever leaving my side.

For those who have had transplants – please don't waste your beautiful gift – for those who are still waiting – I truly believe in miracles – never ever give up hope – stay strong and positive.

This story is dedicated to my donor Aileen my angel in heaven – her family who fulfilled her wishes of being an organ donor – and to my beautiful family Greg, Michael, Aimee, Emmy & Mitch who have always been there for me.

Forever grateful

Tracey Slatter

DOCTORS TRANSPLANT FIRST HEART THAT HAD STOPPED BEATING

In a world first, doctors at St Vincent's Hospital have managed to successfully transplant a heart that had stopped beating for 20 minutes.

The heart was brought back to life, then placed on a machine, before it was injected with a unique preservation solution – developed by the Victor Chang Cardiac Research Institute and St Vincent's Hospital.

The Preservation Solution:

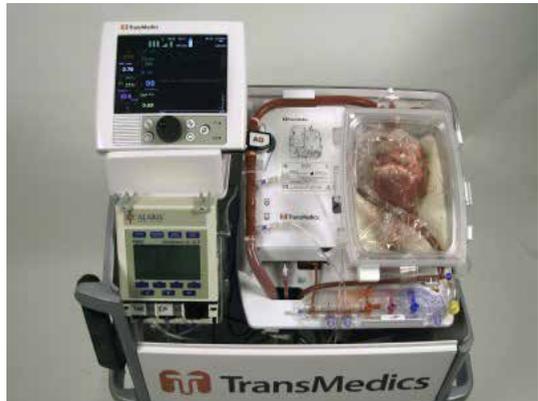
Reduces the amount of damage to the heart

Makes the heart more resilient to transplantation

Reduces the number of heart muscle cells that die

Improves heart function when it is restarted

Limits damage from a lack of oxygen



The preservation solution took 12 years to perfect

In the 30 years surgeons have been performing heart transplants, it has always been a race against the clock. Doctors had just four hours to complete the intricate operation, with the precious organ stored and transported in an Esky filled with ice. But not anymore.

The unique preservation solution and the portable machine extend the amount of time a donor heart can spend in transit from 4 to as many as 14 hours.

Throughout 2014 Professor Peter Macdonald's team successfully transplanted four hearts using this ground breaking technique. Surgeons at St Vincent's hospital anticipate that an extra 30 transplants will be performed per year in Australia and many more around the world. Which means more lives will be saved, and more families spared the burden of caring for a severely ill relative.

This represents a paradigm shift in organ donation and will result in a major increase in the pool of hearts available for transplantation.

Heart transplantation is by far and away the most effective treatment for patients suffering advanced heart disease. But a chronic shortage of donor organs means the life-saving procedure is available to very few people. Tragically many of those who need a new heart will die on the wait list.

"In all of our years, our biggest hindrance has been the limited availability of organ donors. In many respects this breakthrough represents a major inroad to reducing the shortage of donor organs." – Professor Peter Macdonald

Source: www.victorchang.edu.au

Date: October 2016

Did you know AHLTA's Financial Assistance Program is designed to support you and your family when you need it most?

For more information about this program and to find out how we can support you throughout your journey please visit: www.ahlta.com.au

AGM and Christmas Party 2016

Christmas time is fast approaching and that means one thing for us– Christmas Party time! If you're a new member, or you've never attended our Christmas party before, then we encourage you to come along for a day of festive fun, food and good times with like minded people. A BBQ lunch and drinks will be provided on the day.

We'll also be holding a raffle and there will be some AHLTA merchandises available for sale.

AGM To commence at 12PM. We look forward to see you there!



Please rsvp by
Friday 26, November 2016
on Lslater6@gmail.com or
0439 598 205 (Lisa Slater)

We look forward to seeing you
in December.



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 12PM
on **Saturday, 3 December 2016**
at **PJ Ferry Reserve Community Hall**
Cnr Bellevue Parade and Blakesley Road, Allawah NSW 2218

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

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:

- \$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.



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