



# The Biopsy Bugle

Autumn 2016

The Australian Heart  
Lung Transplants  
Association Inc.

Since 1983



## President's Message



I feel a great deal of pride from our latest purchase. The association endeavors to assist our members, and with our most recent purchase of a new observation machine for The

Heart Lung Transplant Clinic at St Vincent's hospital, Darlinghurst, we can honour this (See picture). This machine will reduce waiting times as two triage rooms can be running on clinic days, it can be used in the treatment room as many need ongoing observations throughout infusions or procedures; not to mention the speed and accuracy it takes a blood pressure now making it beneficial to everyone and keeping the nurses very happy.

This is just another item on the list that the association continues to develop in helping our members in clinic. Other recent additions are; the TV in the treatment room, the fish tank and ongoing maintenance, the maintenance of the noddly cars and of course the magazines for you to peruse whilst waiting. The association finds these items important and is always looking for new ideas to make our journey a little easier.

AHLTA Thanksgiving is just around the corner, with the date set for Saturday June 18th, 2016. A non- denominational service is held in the chapel of the Scared Heart grounds, opposite St Vincent's Hospital, followed by lunch, mingling and presentations. This is one of my favourite days, catching up with old friends, meeting new friends, remembering, rejoicing and sharing similar stories. Everyone is welcome. We are looking for people who would like to help organise this event. Please contact Lisa Slater or myself if you are interested.

The Transplant games are on the horizon (September 24th-2nd October, 2016). This year they will be held right here in Penrith, NSW. Please head over to the transplant games website for all the details and start your training. Lets make them the biggest so far.

I am looking for a carer, family member or someone closely associated with Heart or Lung transplantation. As many of you are aware we have a great Facebook group for Heart and Lung Recipients. This is a private page to share stories, support, have a laugh or vent. However, I am aware many people feel left out, as it is for a specific group only. Therefore my next plan is to start something similar for carers,

parents, partners etc only. This is a place you can discuss all things transplant without us knowing. You can catch up with those you've met in hospital while you sit and wait for us to be scanned/ x-rayed / biopsied. I would love to start the group but I believe it should be run by a carer, parent, partner etc and not myself. So if you have an interest in this please contact me. As soon as I have a volunteer we can get it up and running.

The association is always after volunteers or new ways of fundraising. If you would like to

contribute please contact Lisa Slater or myself and we can help facilitate this for you.

Rug up as the temperature starts to drop, keep up your healthy balanced diet and vitamins, stay away from coughs and colds, and remember hand hygiene is paramount to keep infections at bay (that's the nurse talking).

Take care

*Kimberley*

Fortune Favours the Brave.

## AGM and Christmas Party

On 6 Decemebr, we celebrated the 33rd AHLTA Annual General Meeting (AGM) and Christmas party in a packed room at PJ Ferry Hall at Allawah with many of our members, their families and our supporters.



The formal part of the AGM took less than 30 minutes and it was followed by BBQ and drink for everyone at

the party. As usual, the Christmas party was a great opportunity for many of us to meet new people,

have some fun and share our very similar stories.

We thank everybody who came helped us to make the Christmas party another unforgettable night, and we

look forward to celebrating another Christmas party with you in December this year.

## Passing of our young volunteer

Paul Benjamin Goldsworthy  
Passed away suddenly whilst on holidays in Hawaii at the age of 25.

Paul was a willing and enthusiastic volunteer for the AHLTA from 2001 to 2006. He became one of the first Associate Members, when that category of membership was introduced.

With his father Terry, he took care of the BBQ luncheons we held in conjunction with the AGM at North Head Museum.

He put his hand up to volunteer at the Bunnings stalls including our first "trial run" at Bunnings Artarmon before it became an annual event at Belrose. For many years he and his Dad did all the cooking while the rest of us served up the sausage sandwiches and the Doll Ladies peddled their jams and preserves.

In 2004 when it decided to renovate a house at 10 Leichhardt Street in memory of Dianne Boon and call it AHLTA House, Paul then a 15 year old apprentice cabinetmaker talked his boss into donating the materials and Paul installed all the shelving in the kitchen, bathrooms and laundry.

Closer to completion Paul took charge of assembling all the flat pack cabinets, wardrobes and other furniture. He was at the House most Saturdays, working with the team and giving advice and scheduling the activities.

The Association has benefitted greatly from his contribution which was inspired by him meeting a cohort of people struggling with a debilitating illness and displaying courage and perseverance.

This was a talented, loving and generous life cut short before it could reach its potential.

He is sadly missed by all his family and friends and all those lives he touched during his involvement with the AHLTA.

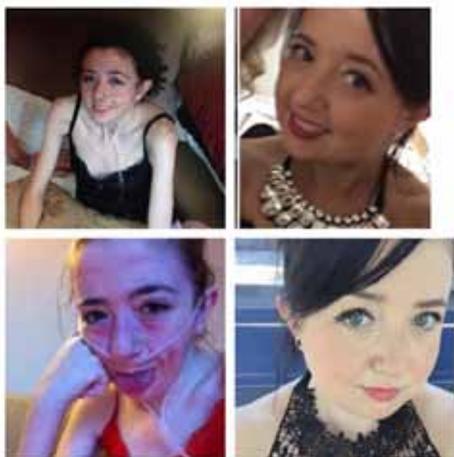
Rest In Peace, Paul.



## Story of my journey

My name is Gemma and I am 26 years old.

My transplant Journey has been an amazing thing, full of ups and downs. I think this is what life is about and at the end of the day it's really important that how we handle it.



Being born with Cystic Fibrosis and diagnosed at 3 weeks old, my childhood and teen years were often filled of memories of being in hospital with what I called when I was young "Just a funny cough and sore tummy" and made many friends through the years with CF, running around

on the wards and playing tricks on nurses. Some friends passed away from this awful disease and some are transplant friends today, and some are still going strong with original lungs.

As I got older I learnt more and more about the genetic condition I was born with and the serious impact it have had on me. It mainly affects the Lungs and digestive system. The biggest cause of death in those with CF is respiratory failure.

From 12 years things seems to get a bit rough, having CF bought on liver disease and I need a liver transplant when I was 13. Diabetic at 14. Kidney stones with open surgery at 15. The list goes on. Somehow, I managed to smile, get on with life and got through year 12 and my HSC, I studied various TAFE courses in design and worked part time at Starbucks in Westmead Children's hospital after high school, the place where I grew up going to treat

Cystic fibrosis.

I have a great support of family and friends, who have always pushed me to do my best and live life how I want too. I tried so much for CF not to hold me back, but as I headed into my 20s, I had to quit work and study, my body was getting weaker and lung function dropping, despite so many treatments, admissions for IV antibiotics (which my lungs became very resistant too) and my weight dropping. Slowly, my mind was giving up too.

In July 2011 when my lung was functioning at 30%, my doctors begun to talk about the big "T" word, Transplant. I knew one day it would happen, yet I was in denial a bit and thought not so soon. Many meetings, thinking, being put on oxygen and bi pap a few months later I was listed in October 2011. I was so scared but I decided I could not live like this anymore. By this stage, I was 34 kilos and 15% lung function and on a wheelchair most of the time. It was the worse 15

months of my life, every day that slipped away I got more worried. I had one false alarm, (funnily enough to the exact date I was called for my liver 9 years before-spooky!) but the lungs were not good. I was ok with this, I knew St Vincent's being the fantastic team of Surgeons, Doctors and Transplant co-coordinators/nurses I knew they were only looking out for ones that would ultimately be worth the wait. That magical call came in February 2013, a week after my birthday. I was operated on at 9pm that night.

All went well having spent two weeks in the hospital, and the rest is history. I've been very blessed and my lungs are still going strong.

To think a stranger out there has saved me, not once but twice now (Liver 2004, Lungs 2013) is the ultimate motivation to live a fantastic filled life and live everyday in their honour and completing everything I want to do in life. They are my hero, as is their family.

Since my transplant I've

been on two cruises, a trip to Cairns to stay with another transplant friend, been a bridesmaid, complete a TAFE course (Finally!!!) returned to work, gone to many concerts as I am a bit of a music buff, done travelling,

set new goals, will see my sister get married this year, become an Auntie one day, I have a bucket list of things I want to do, spent time with my

precious friends and family and many more. Breathing is amazing and should not be taken for granted, something so simple yet people take for granted.

These are a few of the many things I have done. I volunteer at Cystic Fibrosis NSW, work with people to raise awareness for CF and organ donation, and hopefully this year will be applying to go to university



to be a paramedic or nurse to give back what they have done for me- they have helped me so much when I was sick.

Life is wonderful. I have amazing friends, family and what I am doing and where

I am going is where I want to be after all these years of hardship,

I live and love every second, I keep positive and do the best I can to stay healthy.

While you have to look after yourself and sometimes hiccups happen post transplant, I would not have it any other way.

Take care everyone



Health  
NSW Organ & Tissue  
Donation Service

Incorporating  
NSW Bone Bank  
Lions NSW Eye Bank

Part of the  
DonateLife  
network



NSW Organ and Tissue Donation Service

## **Service of Remembrance**

Saturday 28<sup>th</sup> May, 2016 at 2pm

Wesley Centre 220 Pitt St, Sydney 2000



**For all those touched by organ and tissue  
donation and transplantation**

For further details please contact ;  
Alison Barnwell or Clare Lynch Family Support Coordinators  
(02) 8566 1700

### Sugary drinks linked to increased fat levels around vital organs

“People who consume sugary drinks are more likely to develop dangerous fat that becomes wrapped around internal organs,” the Daily Mail reports after a US study found a link between the consumption of sugary drinks and increased visceral fat levels.

Visceral fat is fat that develops inside the abdominal cavity. Having high levels of visceral fat has been linked to an increased risk of developing type 2 diabetes and heart disease.

This study followed around 1,000 middle-aged adults over a period of six years after assessing how often they consumed sugar-sweetened drinks and diet fizzy drinks. Researchers used CT scans to measure the amount of visceral fat each person had.

People who drank one sugar-sweetened drink a day or more had the highest increase in this type of fat, at 852cm<sup>3</sup>, compared with 658cm<sup>3</sup> in people who did not drink them.

But visceral fat accumulated in all the participants. It may be the case that, for many people,

an increase in visceral fat is a consequence of ageing.

The results are not conclusive, as the media has reported – the number and type of drinks was only assessed at the beginning of the study and may have changed over time. There



may also have been other unmeasured factors that could account for the results.

Overall, the results of this study support current UK guidelines to limit the amount of sugar we consume to no more than 30g a day for adults (roughly seven sugar cubes). Sugary drinks have no health benefits.

## Many smokers may have lung disease

More than half of current and former smokers who can pass basic lung function tests may suffer from lung diseases that have gone undiagnosed, US researchers say.

The study in the Journal of the American Medical Association (JAMA) Internal Medicine included nearly 9000 people, aged 45-80, who had smoked at least a pack of cigarettes a day for 10 years.

About half of those in the study 'were considered disease-free based on their lung-function tests,' said the JAMA article.

But when researchers looked at other criteria, including respiratory symptoms, CT scans, medications use and quality of life issues, they found that '55 per cent of the 'disease-free' study

participants had some form of respiratory related impairment'.

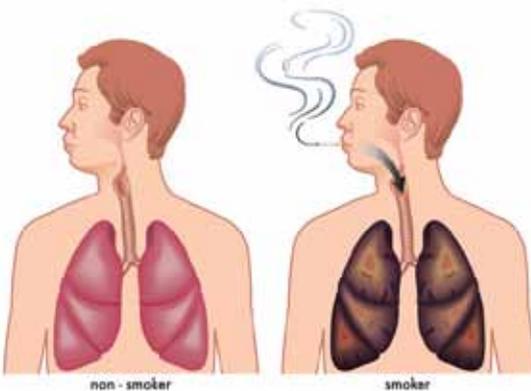
Many were in the early stages of chronic pulmonary obstruction disease, or COPD, which is the third-leading killer in the United States.

Forty-two per cent had emphysema or airway thickening, while 23 per cent had significant shortness of breath.

'Smokers who have 'normal' lung-function tests often have significant respiratory disease. Many of those smokers likely have the early stages of chronic obstructive pulmonary disease,' said Elizabeth Regan, lead author and assistant professor of medicine at National Jewish Health.

'We hope these findings will help debunk the myth of the healthy smoker and highlight the importance of smoking prevention and cessation to prevent lung disease and other long-term effects of smoking.'

Source: [www.skynews.com.au](http://www.skynews.com.au)  
Date: June 2015



## Upcoming events- Save the Date

### 1. Thanksgiving servie

Our next thanksgiving servis will be held on Saturday, 18 June 2016 at 11am. We are actively looking for a volunteer who can help us with organising this event. Please email us on [info@ahlta.com.au](mailto:info@ahlta.com.au) if you like to know more about how you can help.

### 2. Bunning's BBQ

Our Bunning's BBQ will be on Saturday, 13 August 2016 at Belrose, NSW. If you would like to know how you can help on the day please contact Lyn on 0403 344 048.

### 3. Stalls

Our Bi-monthly stalls are held in the foyer of St Vincent's Public Hospital in Darlinghurst from 10am until 3pm. Our next stall day will be on Tuesday, 3 May 2016. If you would like to help out on the day please 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' 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 \_\_\_\_\_

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



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