



the Circulator

Heart and Lung Transplant Trust (Victoria) Inc A0037327C/ABN 68 585 966 022

First Quarter | 2017 | Issue No. 87

Happy New Year!



Contents

President's Message	2	Travel After Transplant	5	The HLTTV's End of 5 Year BBQ	13
A note from the editor	3	Camille's Melbourne Marathon	8		
Meet Our New Treasurer	4	Transplant Anniversaries	11		



President's Message

Welcome to the first edition of The Circulator for 2017! I still can't quite believe that 2016 is over, it seems only yesterday we were gearing up for the Tour de Transplant. We hope all our members, supporters and friends had a fun and relaxing festive season, especially some of our new members who have been celebrating their first Christmas since their transplant. We also know that some of our members have lost loved ones this year, and our hearts go out to those families because we know that the Christmas period can be especially difficult.

Our AGM was in November, and we said a sad farewell to our Treasurer Lauren Dinnar, who has been part of the committee for two years. However, we are excited to welcome three new committee members – David Pidgeon (our new Treasurer), Brandon-Lee Rocco (our new Events Officer) and Rebecca Berry who has come back on the committee as an (extra)Ordinary Member. It's always great to have new faces and fresh ideas on board and I'm sure that 2017 will bring lots of great things (plus some hard work).

As I write this we are not too far from having our first committee meeting of the year. I know that Rocco is keen to throw some more social events for our members and supporters, so keep your eye on The Circulator, our Facebook page and your email for details through the year. A few of us are also working more closely with the hospital to identify and address any issues in the transplant clinics. There may be opportunities for our members to share their opinions and ideas as well, so we'll keep you posted on any advocacy or feedback opportunities as they arise. And we're always looking for volunteers to share their transplant stories in The Circulator, present their experiences at education sessions and also contribute to the work of the HLTTV in a variety of ways. If you think you have a skill to share, or would like to get involved, please contact me directly (president@hlttv.org.au). Finally, this year we are trying something a bit different and we're holding our Easter BBQ on a Saturday (1st April – no fooling!). Please save the date. More details will be coming out soon, but we're planning on having a bit of

entertainment and fun for all ages, so it would be great to see as many of our members, supporters and friends come along as possible.

We hope you enjoy the last days of summer (don't forget to slip, slop, slap!) and hopefully we'll see you on April 1st.

Louisa Walsh
President

Committee Contacts

President: Louisa Walsh
Email: president@hlttv.org.au
0427 509 042

Vice President: Camille Condon
Email: vicepresident@hlttv.org.au
0404 084 625

Secretary: Emily Adamson
Email: secretary@hlttv.org.au

Treasurer: David Pidgeon
Email: treasurer@hlttv.org.au
0421 134 805

Membership Officer: Vanessa Scott
Email: membershipofficer@hlttv.org.au 0417 384 974

Patient Support Officer: Carla Bondini
Email: patientsupport@hlttv.org.au

Circulator Editor: Claire Stubber
Email: circulator@hlttv.org.au

Ordinary Member: Martina McArdle
Email: martina@hlttv.org.au
0409 957 492

Postal Address

Heart and Lung Transplant
Trust Victoria
PO Box 25036
Melbourne 3004

HLTTV Committee Meeting

Date: Tuesday 14th February

Time: 7:30 pm

Place: Seminar room, level 5,
Centre Block.



You can also join members of the committee for an informal get-together at 7pm in Alf's cafe. All welcome!

New HLTTV lapel badges and membership information



HLTTV have new lapel badges! Purchase yours now for \$5.

New members will also receive a lapel badge in their Welcome Kit.

Remember - your membership fees help us continue the good work that HLTTV does for people waiting or who have had a heart and/or lung transplant.

A note from the editor

Hello Reader,

Happy New Year! I hope that this year brings health and happiness.

Your plans for 2017 may include travel, in which case Louisa Walsh, our president has you covered. Louisa has written an article that contains a lot of useful information for those who plan to travel post transplant. Keep an eye out for HLTTV committee members in the photos,

they prove that travel is possible and enjoyable post-transplant.

This edition gives us the opportunity to introduce HLTTV's new treasurer David Pidgeon. We welcome him and Brandon-Lee Rocco, our new events manager, to the HLTTV. We welcome familiar members back to the committee and thank them for their dedication and commitment.

You can see the results of the committee members' hard work in the last pages of this edition. For the end of year barbeque the

HLTTV, once again, managed to create a successful and enjoyable event for HLTTV members and their families. If you haven't attended one of these events they are well worth attending for those both pre and post-transplant. It is a great opportunity to socialise with those who know what you're going through. Your next opportunity to attend a HLTTV barbeque will be April 1st 2017. We hope to see both new and familiar faces there.

Happy reading!
Claire - Circulator Editor

Donations to the Heart and Lung Transplant Trust (Victoria) are fully tax deductible and easy to do using www.givenow.com.au. Simply visit <http://givenow.com.au/hlty> and follow the prompts.



A great place to relax

Heart to Heart House Barmah Vic

Bookings & Information

Martina McArdle
Mobile 0409 957 492

Laraine Anderson
Tel 03 9770 7197
Mobile 0418 599 745



HLTTV's valued program partner

Since May 2012, HLTTV have been thrilled to partner with the Park Regis Griffin Suites to provide affordable, accessible and practical accommodation for regional transplant recipients. Park Regis Griffin Suites have partnered with our Second Chance Accommodation Program to provide six, 1 bedroom apartments for the use of transplantation recipients. Situated between Melbourne's city centre and St Kilda Beach, the Park Regis Griffin Suites features include a range of different accommodation options, an onsite cafe/bar and a tram practically at the front door.

Park Regis Griffin Suites
Phone | (03) 8530 1800
Location | 604 St Kilda Road,
Melbourne
Email | griffin@parkregishotels.com
Web | www.parkregisgriffinsuites.com.au

We highly recommend the Park Regis Griffin Suites, and the Stay-Well Hospitality Group. For those looking for accommodation close to The Alfred, make sure you check with the Park Regis for any available discount rates.



Meet Our New Treasurer

Hello to everyone associated with HLTTV!

My name is David Pidgeon and I joined The Trust's Committee in November, taking over as Treasurer from Lauren Dinnar. I am delighted to be part of what seems like a really talented and energetic team!

Here's a little bit about me:



I hail from the UK and moved to Melbourne just over 6 years ago with my wife, Fiona. We both proudly obtained our Aussie citizenship last Australia Day, although I have to admit I still find it difficult to barrack for the Baggy Greens in the cricket! I don't actually have a specific transplant story that connects me to the Trust, but I was very keen to get on board with a charitable cause, so was very excited when I started chatting to Emily about the opportunity to join the Committee when it arose.

Professionally, I am a qualified Chartered Accountant and work for a US owned personal care Company here in Melbourne as

its Financial Controller for its Asia Pacific region. I previously worked in Europe, including 5 years in Milan, Italy, which fed my passion for travel, skiing and a taste of 'La Dolce Vita'! Fiona and I enjoy the outdoor spaces that Melbourne has to offer and we both play tennis and golf, and I'm currently coming to

the final few matches of a club cricket career that has spanned (dare I admit it?) 40 years...including 15 years as club treasurer and various other roles. I'm particularly looking forward to learning more about the Trust and of course meeting its members, plus contributing what I can to add some value in the years to come.

David

p.s. I'm the one on the left in the picture.

Quick Tuna and Avocado Salad

Ingredients

- 315 g tuna in spring water, drained
- 300 g can no-added-salt cannellini or butter beans, drained
- 1 tomato, chopped
- 1 avocado, seeded and cubed
- 1/2 lemon, juiced
- 1 tsp lemon rind, grated
- 1 tbs basil leaves, chopped
- 2 tbs low-fat natural yoghurt
- pepper, to taste

Method

1. In a bowl lightly fold tuna, beans, tomato and avocado.
2. In a small bowl mix other ingredients together to make the dressing and pour over tuna mixture.



Travel After Transplant

One of the common goals for people after transplant is to travel. Transplant recipients have often had an extended period of being unwell and have missed out on things like work and holidays. Travel – especially overseas travel – is often a motivator for during recovery post-transplant, and can be a great reward for getting through this tough experience.

However, post-transplant travel can also be daunting and scary. There are risks involved – what if I get sick overseas? What is something happens to my medication? There are also lots of additional considerations for people with transplant – such as getting doctor's letters and finding an insurance company that will grant you insurance for your transplant.

In this article I will cover some of the common travel questions we hear at the HLTTV. We won't cover everything here, and, of course, before you travel it is essential to speak to your treating team and ask any questions or discuss any concerns you have.

Can I get travel insurance which covers my transplant?

The short answer is yes. However, finding insurance which covers your transplant and any other pre-existing conditions can be difficult, and will cost more. There is also no guarantee

that you will be able to find insurance cover. To increase your chances, follow these steps:

- Talk to your clinic about your travel plans. They may have suggestions for where to go, where to avoid, any health checks or treatment you should have before you go, and also contacts for transplant centres should you get unwell while overseas. Your doctors and clinic coordinators will also be the ones who need to complete sections of your insurance forms – so keep them informed of your plans and needs. GPs can



Committee Member Martina Relaxing in Bali, 2015

also help with completing any insurance paperwork which can take the pressure off the busy transplant clinics.

- Allow enough time to get your applications submitted and reviewed. Applications for insurance which covers pre-existing conditions often require extensive paperwork, including doctors' reports. You should start applying for travel insurance at least 6-8 weeks in advance of your trip, which will also give you time to change your travel plans should you not be able to get insurance.
- Submit applications to multiple insurance companies at the same time. Insurance applications will have a question about whether you have been denied insurance from any insurance company in the past. You can answer 'no' to this question on multiple simultaneous applications if you have never applied for insurance, or never been denied. Any denials of insurance in the past will count against this insurance claim. While time consuming at the start, submitting multiple applications saves time in the long run and can increase your chances of getting insured. We also recommend calling companies before you submit applications to enquire about whether or not they cover transplant – this can also save time.
- The fewer medications you are on, the more likely you are to get cover. Don't stop medications just for the sake of a holiday, but have a conversation with your transplant clinic about medications that you can take a break from during your holiday, or if there are medications that come in a combined form.
- You are more likely to get cover if you have not had

Travel After Transplant

a hospital admission for infection or rejection in the past 2 years.

- The likelihood of getting covered, and the expense of the cover, is partly determined by where you are travelling. Generally, travel insurance is most expensive, and pre-existing condition cover most difficult to get, for places where health care costs are most expensive, and the insurance company will have to pay a lot of money if you get sick (such as the USA). You may like to take this into account when planning your holiday.
- Even if you do get cover ALWAYS read and understand the product disclosure statement (PDS) before you pay for it. It is important to understand what your travel insurance will and won't cover – understand exactly what they mean when they say they will cover pre-existing conditions.
- Talk to transplant recipients who have travelled recently. Insurance companies change their policies all the time – a company who would insure a transplant recipient 2 years ago may no longer do it. Ask other transplant recipients where they have had success recently and apply with those companies.

Transplant Australia members

can get special access to travel insurance. Membership of Transplant Australia is \$15/year. For more information about membership or travel insurance through Transplant Australia check out their website: www.transplant.org.au or call 1800 027 757

What about Reciprocal Health Care Agreements?



Membership Officer Vanessa in Scotland 2014

Australia has Reciprocal Health Care Agreements in place with New Zealand, the United Kingdom, the Republic of Ireland, Sweden, the Netherlands, Finland, Italy, Belgium, Malta, Slovenia and Norway. These agreements mean:

- Australian residents can get help with the cost of essential medical treatment when visiting these countries; and residents of these countries can get some essential medical treatments while visiting Australia.

Reciprocal Health Care Agreements do not replace the need

for travel insurance, and are for essential medical treatment only. This may include an admission related to your transplant if a specialist decides that treatment is required to prevent your condition getting seriously worse and you are too unwell to travel back to Australia. Reciprocal Health Care Agreements will not cover costs of outpatient medications, so it is important to take enough medication to cover the trip and any emergencies. Make sure you talk to your transplant clinic about the likelihood of treatment under the Reciprocal Health Care Agreement where you are going.

Are there any issues with taking medications overseas?

Generally, there are no issues with taking your transplant medications overseas. You can easily take up to three months' worth of medications in your luggage. Important things to consider are:

- Get a letter from your clinic before you travel which outlines all the medication you are on. You will also need doctor's letters for any fluids or syringes you need to carry into the plane with you (for e.g. insulin).

Check on the Smart Traveller website (<http://smartraveller.gov.au>) for any medication restrictions for the country you are going to. Most countries don't restrict personal medications (especially when accompanied by a doctor's letter) but sometimes medications which can be addictive (such as co-

Travel After Transplant

deine and other pain killers) may be restricted.

Leave all medications in their boxes/bottles with their pharmacy labels with your name on them. If you are stopped, this makes them easy for customs staff to identify the medications and verify that they are yours. Take more medication than you need for the time you are away just in case some get damaged/lost, and split carrying your medication between your checked luggage and hand luggage just in case either goes missing.

Talk to your doctors about managing changes in time zones for medications that you need to take at the same time each day.

How do I stay well while I'm travelling?

Travel can open us up to many new experiences – not all of them great! Being confined on long flights, mixing in crowds, eating strange foods - can all put us at risk of infection. It is not uncommon for anyone to get a bit unwell when they travel, but people who are immunosuppressed are potentially at higher risk. Things to consider are:

- Hand washing is your best friend. Wash your hands and use alcohol sanitiser rubs regularly. This easy step really will prevent you from getting lots of germs and is the best defence to stay well while on the road (or in the sky).
- Know the risks in the country you are going

to. Some destinations are more risky when it comes to infectious illnesses than others. Make sure you know how to minimise those risks (not eating certain foods, only drinking bottled water, etc), and if you don't feel comfortable travelling there, choose another destination.

- See the travel doctor before you go. This will ensure you are up to date with your vaccinations.



Vice President Camille, Japan January 2017

You can also get a handy kit of 'rescue medications' just in case things do go wrong. There is a travel clinic at The Alfred that is covered by Medicare – just ask your transplant clinic for a referral!

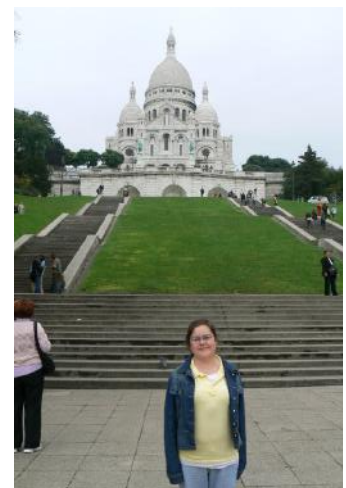
- Speak to your transplant doctors for advice. They may be able to prescribe you some emergency medications to take with you, or give you contact details for their colleagues in the country

you are visiting just in case things do go wrong and you need some professional advice.

Travel is a wonderful thing, and is often even more special for people post-transplant who maybe experiencing going overseas for the first time. It's important to know that even though you are post-transplant, you can travel safely and with confidence. Many of our community members have great travel stories and advice that they would be willing to share with you – as well as hot tips about destinations!

If you'd like to chat with someone about their experience of travel post-transplant, please contact Carla – our Patient Support Officer (patientsupport@hlttv.org.au) and she will either hook you up with a fellow recipient traveller or chew your ear off about her trip to South America!

- Louisa Walsh



Circulator Editor Claire, Paris 2006

Camille's Melbourne Marathon

For the third year running, Team HLTTV entered the Melbourne Marathon Festival on Sunday October 16th 2016. This year, we chose to participate in the 3km walk event as we really wanted to encourage more transplant recipients to join in.

When I first started organising this years team back in

June, I had no idea that I'd be lucky enough to be able to catch multiple viruses, a bacterial infection and a fungal infection - ALL at the same time. I was sick for the majority of August and September and ended up spending a total of 22 days in isolation

on 5 East Ward (that's the same amount of days that I spent as an inpatient post double lung transplant in 2013).

worried that as Team Organiser, I was going to have to pull out and leave my poor team members in limbo. Thankfully in the few days before the walk, my lung function was back up to around 49% of predicted.

There was lots of BOM weather monitoring the week before the walk, with typical Melbourne predictions of rain, hail and shine, all in one day. Everyone was scrambling, trying to find plastic ponchos 'just in case', but in the end we were presented with just about perfect



Group Shot of the Participants before the Melbourne Marathon



The Team at the Start Line

While in hospital my lung function dropped to around 40% of predicted, and I was a bit

conditions for a lovely stroll.



Camille, her sister and her nephews at the start



The rest of team HLTTV

The day began with all team members meeting at the steps of Rod Laver Arena for team photos – except that someone forgot to tell us that those stairs are currently a construction site! Thanks to modern technology we all managed to find each other just in time for a few quick snaps before we headed for the starting line.

We took off with gusto straight

Camille's Melbourne Marathon

up the hill on Batman Avenue towards Flinders St. The course meandered back down Batman Avenue, through Birrarung Marr, up the pedestrian walkway and onto William Barak Bridge. Off the bridge and onto Brunton Avenue, before the magic of walking onto the hallowed turf of the MCG for the final lap.



During the Walk

All of our team members did a magnificent job of encouraging each other through the day – we're definitely not marathoners, but we all put a lot of 'heart' into our participation on the day. For me personally, I was a little worried that I wouldn't make it, but I just had to remember not to try and talk while

walking up hill while huffing and puffing! It just goes to show that even when you've had some health problems, you can still achieve great things.

With our largest team of participants to date, I'd like to give a special thankyou to:

Melissa, Matthew and Reegan Baker
Rebecca Berry and Ronel Burger
Jose Elorza and Danielle Nikolic
Damien Pimpini and Andrea Wallis
Linda, Miles and Natalija Stan-kovic
Rachael, Mason, and Noah Tose-land
Vickie and Olivia Datson
Samantha Kruber and Thomas Postlethwaite
Colin and Cyanne Lofts
Xavier Condon
Lara Dunstone and Sue Fletcher

At the time of writing this wrap up, our fundraising tally for the event is sitting at \$1663

The Fundraising site is open for 30 days after the event
<https://melbournemara->

thon2016.gofundraise.com.au/page/HLTTVMelbMara16

Keep an eye out on our Social Media pages next June, as we'll definitely be back next year



Medals!



Some of the Girls on the MCG



The Scene at the MCG, Team HLTTV Made It!

Become a member now



Heart and Lung Transplant Trust (Victoria) Inc.

Membership Form

Name:

Partner's name (if applicable):

Address:

Postcode:

Telephone:

Mobile:

Email address:

Date of birth:

New member

I wish to become a member of the Trust

OR

Existing member

I wish to renew my membership

I wish to receive my copy of 'The Circulator' by email:

Yes

No

Recipient (Please complete information regarding Transplant Type, Operation, Month and Year – this allows us to celebrate transplant anniversaries if you consent below.)

Lung/s	Month	[]	Year	[]
Heart	Month	[]	Year	[]
Heart & Lung	Month	[]	Year	[]
Other (please specify)	Month	[]	Year	[]

Are you happy for this information to be included in 'The Circulator' newsletter 'Transplant Anniversaries' each year? Yes No

OR

Pre-transplant (Waiting list)

OR

Carer/other/supporter (please specify)

Signature: **Date:**

Membership for Pre-transplant members is free. An annual fee of \$15 applies to all other category of member. A membership reminder will be included with the Winter edition of The Circulator each year. Prompt payment on receipt of a membership invoice is appreciated and we are grateful for any donations. Donations over \$2 are tax deductible.

Please return this form to:

Membership Officer, Heart and Lung Transplant Trust (Victoria) Inc.
PO Box 25036
Melbourne Victoria 3004

Members may also join online and pay membership and donation via direct bank transfer. Please visit <http://www.hlppv.org.au> and follow the 'Membership' links.

Transplant Anniversaries - We Wish You Many More

February

Heart:

- Margaret Neilson, 2009
- Barry Parsons, 1997
- John Winter, 1992

Lung/s:

- Ken Gain, 2004
- Michael Kinniburgh, 2016
- Kirsten Larsen, 2003
- Frank Lineen, 2008
- Ronnette Williams, 2015
- Camille Condon, 2013

- Heather Hill, 2006
- Toni Miles-Bennett, 2011
- Arthur Pape, 2016
- Suellen Pettersen, 2002
- Yehia Ragheb, 2015
- Jon Rolfe, 2009
- Betty Sammartino, 2011
- Lois Scott, 2012
- Robyn Scott, 2015
- Chetan Shah, 2016
- Vicky Yfantis-Cocossis, 2013

Heart and Lungs:

- Carla Bondini, 2014
- Jose Lopez, 1990

Please Note: If you or your loved one has had an attribution made in error or you no longer wish for the anniversary to appear in *the Circulator* please notify the membership officer at:

membershipofficer@hlttv.org.au

If you have sent notice to any other address within the past year please send a reminder email to the membership officer.

March

Heart:

- Gary Down, 2012
- Christiaan Gerritzen, 1995
- Sue Konieczny, 2008
- Edward O'Bryan, 1990
- Matthew Orchard, 2014
- John Prior, 2008

Lung/s:

- Camille Condon, 2013
- Judi Groves, 2012

Heart:

- Tony Allan, 1994
- Nicole Armstrong, 2014
- Ivan Clark, 2015
- Les Doughty, 2011
- Graham Percival, 2016
- Bill Saunders, 2010
- Bill Vickers, 2003

Lung/s:

- Christine Flack, 2014
- Bruce Vernon, 2015

Donate now

I/We would like to make a donation to the Heart and Lung Transplant Trust (Victoria) Inc.

Name:

Address:

Postcode:

Donation: \$

(Donations over \$2.00 are tax deductible)

Please send to: Treasurer Heart & Lung Transplant Trust (Victoria) Inc

PO Box 25036, Melbourne, Vic, 3004

Please visit <http://www.hlttv.org.au/> and look under 'Quick Links' and choose one of the 'Donate Now' links.

The Circulator editorial team is keen to review books, magazines and articles that may be of interest to the transplant community. We're also keen to promote the work of those who have embraced their 'second chance' at life to explore their creativity or pursue their dreams.

Contact Claire by email | claire@hlttv.org.au

Items for review can be posted | Editorial team C/O PO Box 25036, Melbourne, Vic, 3004.



Heart and Lung Transplant Trust (Victoria)

Our Vision, Mission & Values

Our Vision is for a bright and active future for all those involved with

or in need of a heart or lung transplant.

We actively encourage organ donation and support The Alfred Hospital Melbourne, the Transplant Team, patients, recipients, their families and carers throughout the journey.

Our Values

Hope | We provide a sense of confidence, belief and realism throughout the experience.

Leadership | We lead and promote a focus on caring, advocacy, support and community to those who share in the transplant journey.

Teamwork | We believe our success depends on how well we interact and communicate with others. We inform, network, collaborate and partner with all relevant stakeholders.

We have a bias towards action.

Trust | Our integrity is fundamental in all that we do and stand for. We act ethically and honestly

at all times. We do what we say.

Vitality | We approach our task with compassion, understanding, strength and joie de vivre.



Are you involved in a business which could provide discounts on goods or services for HLT-TV members? We're looking to increase benefits for our members and we'd love to hear from businesses that would like to get involved with the work we do either through providing discounts or supporting us in other ways.

Email our President, Louisa, via:
president@hlttv.org.au
to find out more!

Buddy Program

We are looking for people post-transplant to volunteer for our new buddy program! People who are waitlisted for transplant will be given the option to take part in the program and be matched with a volunteer 'buddy'. This initiative aims to assist those pre-transplant with answering any questions or concerns they may have around the transplant process, and to provide moral support by sharing your own experiences.

If you'd like to become a buddy, please contact Carla at patientsupport@hlttv.org.au.

The HLTTV's End of Year BBQ



HLTTV's End of Year BBQ



HLTTV's End of Year BBQ



Please Join Us



Heart & Lung Transplant Trust (Victoria) Inc

Bringing The Alfred transplant family together.

2017 EASTER BBQ

Saturday 1st Of April 2017

Fawkner Park - Lawn 14

Next To South Yarra Primary School,

Parking on Pasley Street.

11am - > Onwards

Musical Performances

with Special Guest - Steve Sedergreen

Easter Egg Hunt & Raffle

Prize For Best Easter Outfit!!!

BYO Chairs

Gold Coin Donation Appreciated

For any inquiries or donations please contact:

Brandon 0401911946 or Martina 0409957492

