



the Circulator

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

First Quarter | 2016 | Issue No. 83

Tour de Transplant Two Weeks Away!



Tour de Transplant 2016 recipient rider group - L to R Matthew Orchard, Louisa Walsh, Phil Anderson (TdeT Ride Leader), Rebecca Berry, Larry Virtue, Jon Rolfe (TdeT Subcommittee Chairman). Photo Ian Stubber.

In this edition:

President's Message	2	Living with Lung Transplantation	8-9
Getting to know	4	Transplant Anniversaries	10
Transplant story	5	Easter BBQ	12
Tour de Transplant	6-7		



President's Message

Happy new year to all our members, supporters and friends! We hope you had a great festive season, and are coping with the hot and humid weather we have been having.

With our AGM in November we had some changes on our committee. We'd like to welcome our new committee members – Emily Adamson, Secretary; and Carla Bondini, Patient Support Officer. I have now taken on the role of President and filled the vacancy that we had throughout 2015. Camille Condon has stepped up into the role of Vice President. Vanessa Scott, Lauren Dinnar, Martina McArdle and Jeff Campbell are remaining on the committee in the same roles they held during 2015. Sadly, we also had to say goodbye to a couple of committee members - Belinda MacLeod-Smith, who was an invaluable committee resource as our Secretary, and Claire Stubber, who has stepped away from the Circulator Editor role.

There is no rest for the wicked, and the new committee has launched into 2016 already. The Tour de Transplant is only 4 ½ weeks away as I write this, and it is shaping up to be an excellent event. I will be riding this year, and I can't wait to be out with the crew on the Great Ocean Road. Even if you're not riding the Tour, you can be involved – we encourage all our members to head along to the Geelong Dinner on Saturday 5th March, or welcome the riders home at the Easter BBQ on Saturday 6th. You can find further details for both later in this edition of The Circulator.

In this edition of The Circulator you'll also find a follow up on the study that Dr Chi Li has been conducting around the services that the lung transplant unit provides. He has also put a call out for people from the transplant community to lend their voices to shaping The Alfred's services.

I would encourage all our members to consider getting involved in this work, so we can ensure that the transplant services are responsive to our needs – and the needs of all transplant recipients now and into the future.

In this edition you'll also meet Megan O'Leary – the new social work assistant working across both the heart and lung transplant units. The HLTTV is proudly funding Megan's position – she is helping to coordinate our Second Chance Accommodation Program, but also assisting with all those practical needs – housing, financial, support – that come with having a transplant or being on the transplant waiting list. We're really excited to work with Megan, and hope that her role really helps to support the Social Workers at The Alfred in their roles as well.

Finally, we are still looking for a new Circulator Editor. The Editor role is a great chance to be part of the committee in a vital role where you can share your creativity with all our members and supporters. If you'd like to find out more about the role, please contact me directly.

I hope to see many of you either in Geelong or at the Easter BBQ! Bring on 2016 – it's going to be another fabulous year for the HLTTV.

Louisa Walsh

President of the Heart and Lung Transplant Trust (Victoria)
president@hlttv.org.au
0427 509 042

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: Lauren Dinnar
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

Events Coordinator: Jeff Campbell
Email: events@hlttv.org.au
0425 782 830

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

Cruise4Cale

On Saturday 17 th October 2015, Geelong Car Cruise (GCC) organized a car rally in honour of Cale Reed. Cale was a young heart transplant recipient who sadly passed away just a few days before the rally was held. Cale was a keen member of the GCC , driving his Ford EF Falcon.

The GCC was set up so young car enthusiasts in Geelong and surrounds could meet in a safe environment and share their love of cars.

The Cruise started at Bunnings North Geelong, and finished at Bunnings in Waurin ponds. Over 1200 people - family, friends, supporters and guests – along with 500 cars - attended the Cruise. Bbqs, raffles, auctions and wristbands contributed to the very generous donations on the day.

A grand total of \$5106.00 was raised from the Cruise 4 Cale fundraiser and was donated to The Heart and Lung Transplant Trust Victoria.

Our thanks go to Travis Collins and The Reed Family for their support of the HLTTV, especially during such a difficult time for Cale's family and friends.

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/hlttv> and follow the prompts.



A great place to relax

Heart to Heart House Barmah Vic

Bookings & Information

Martina Appelman
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.



Getting to know - Megan O'Leary

Megan has recently started as a Social Work Assistant and is working across the heart and lung transplant teams at The Alfred. Make sure you say hi to her next time you're in at clinic!

You're new to The Alfred transplant teams. Can you tell us a bit about your background and how you came to be working at The Alfred?

I've been interested in working in Health for as long as I can remember. After finishing school I completed a Bachelor of Science, majoring in Psychology, at Monash University. In 2015 I began my Master of Social Work through Monash University before transferring into a Postgraduate Diploma of Psychology for 2016. Before working at the Alfred I worked as a Research Assistant for a Youth Drug and Alcohol Service. My first exposure to Alfred Health was in 2014 when I completed a placement with their Child and Youth Mental Health Service (CYMHS). Through my time at CYMHS I gained a great appreciation for the fantastic staff, and inspiring work done by Alfred Health and was very excited to be offered an opportunity to join the team at the Alfred Hospital.

The social work assistant position is a new job within the transplant units. Can you tell us how this role will help people before and after transplant?

Part of my role as the social work assistant is to aid patients both pre and post-transplant in accessing support. This includes assisting in the filling out of financial assistance forms as well as setting up accommodation for patients who are travelling from interstate or country Victoria. I am also responsible for keeping records on accommodation that is provided to transplant patients, in order to make sure that we are effectively catering for the needs of patients and no one is slipping under the radar.



How is the assistant role different to that of the social workers?

The Social Workers have a much wider role within the transplant service and are kept very busy assisting patients in a variety of ways throughout their whole journey. My role is more focused on pre and post-transplant support where patients are in need of assistance in order to access services before entering hospital and after being discharged.

What have you found out so far about transplant or the transplant community that has surprised you?

I was surprised to learn that the Alfred is one of only a select few hospitals in Australia that offers Lung Transplant. It is quite impressive and inspiring to watch everyone in the Lung Transplant team working together, each adding their own little piece, in order to achieve such a life changing goal.

What do you like about working with people who have transplants?

There are a number of great things about working with people with transplants! Watching patients' quality of life improve post-transplant is very rewarding! Being able to help make the whole transplant process even a tiny bit less stressful through assisting

with any paperwork/ accommodation needs is also a great feeling!

What do you do for fun?

I enjoy travelling, seeing new places and planning my next adventure. I spend a fair amount of time catching up with friends at the local park as we all attempt to wear out our energetic dogs. I love animals and have spent a lot of time working with dogs and horses over the years although time constraints has made this more difficult of late.

What's your favourite food?

I could live off Avocados! My guilty pleasure would have to be Thai food though. And of course I'm quite partial to chocolate!

What's the best holiday you've ever been on?

From June to August last year I spent 2 months travelling all around Europe visiting Iceland, Scotland, Ireland, England, Belgium, Holland, Germany, Poland, Austria, Czech Republic, Hungary, Slovenia, Slovakia, Italy, Switzerland and France. I particularly enjoyed experiencing snow for the first time in the Swiss Alps and exploring the amazing architecture and rich history of Budapest.

Are you a cat person or a dog person?

I love both! However I am probably slightly more of a dog person. I currently have a 2.5 year old Dalmatian named Elsa and a 6 year old cat named Holly.

How do people get in contact with you?

I am contactable through the Lung Transplant Outpatient Clinic on 0417 046 210

Andrew Hunt's transplant story

Andrew Hunt is a HLTTV who regularly updates our readers on his transplant journey. This is his third instalment since his 2008 heart transplant. Take it away, Andrew...

STILL HAVEN'T PURCHASED THAT ROCKING CHAIR, AS YET!

Just a quick update on a few things post my heart transplant 29 January 2008.

In my previous two short stories, I reckoned I wasn't ready for the rocking chair and luckily for me that remains the case.

In July 2008, after fifteen months off work, I returned to my role in Human Resources in the state public sector where I worked on a part-time basis until leaving in July 2013. My partner, Dana, also left the state public sector in September 2013.

Since leaving the state public sector, I have completed a Certificate IV in Employment Services and done a bit of job searching and, as I have a keen interest in HR and employment related matters, I am volunteering in the not-for-profit sector at an organisation called DOME ("Don't Overlook Mature Expertise"), where I interview and provide support to mature age job seekers.

Since my heart transplant we have done a bit of travel, including Sydney, Perth, The Great Ocean Road (a few times), Broken Hill and taken "auctioned" holidays in Victor Harbour, Portland, Wallaroo, Cape Jervis, Marion Bay and Robe. Pre transplant, I was generally stuck at home too sick to do anything.

Not working since July 2013 has provided much time for reflective thought. We will never forget arriving



at the Alfred 29 January 2008 to discuss the implantation of a Left Ventricular Assist Device (LVAD), only to be informed by 1 pm that a donor heart was available - amazing luck!

As I continue to power walk on the treadmill at my gym, I frequently recall my pre transplant "life" when I was breathless just getting out my chair, my lungs filling up with fluid, the constant insomnia, the timely shocks from my defibrillator, the unrelenting dehydration caused by extreme doses of frusimide, the toxic side effects of amiodarone, the frequent inpatient stays, being on and off work so often and feeling awful, most of the time.

I still become emotional after power walking 8 kms on the treadmill at my gym in just under sixty minutes (never any jogging or running), a speed I would never imagined possible while sitting in my wheel chair in Fawker Park early 2008.

Best wishes and kind regards to everyone.

Cheers Andrew and Dana.

Tour de Transplant - Jersey Presentation

The Tour de Transplant bike ride raises funds for HLTTV's Second Chance Accommodation Program as well as promoting community awareness of organ & tissue donation.

In 2014 the inaugural event raised a staggering \$250,000 for the program therefore enabling six apartments to be available for transplant families for the next two years. The 2016 Tour will ensure we can continue to provide these apartments to these families in desperate need.

There are five women and thirty men on the 2016 Tour, with the average age being 47, with the youngest rider 24 and the eldest 66. In geographic representation we have riders from New South Wales, Australian Capital Territory, Tasmania & Victoria.

There are four transplant recipients riding; Rebecca Berry (lungs), Matthew Orchard (heart), Larry Virtue (heart and our oldest rider) and Louisa Walsh (lungs). As well as riders from the transplant community of family and friends, the rest of the group consists of riders from 2014 returning, some with friends, and new sponsored riders & committed cyclists.

On the evening of 3 February, Bells Hotel hosted our rider jersey and sponsor presentation, expertly MC'd by Gerry Hanily. The event was a great success! Riders, sponsors and friends heard all about the work of the HLTTV, the amazing work of The Alfred transplant units, and the important that the Second Chance Accommodation Program plays

in easing the financial burden of transplant on recipients and their families.

Riders were also briefed on the operational matters of the Tour, and heard from the Tour leader - Phil Anderson OAM - about what would likely follow during their five day journey. Riders were then individually presented with their riding jerseys by Phil.



Photo Ian Stubber

With the Tour starting on Wednesday 2 March, the Task Force is very busy making sure everything is set up and that it will be a wonderful experience for all the participants. Meanwhile our riders are incredibly active, both training and fundraising; they have currently raised over \$65,000 and we are hoping to beat our 2014 target with your help.

How can you help?

HLTTV members can support the event by:

- Donating online at <http://donate.tourdetransplant.org.au>

- Attending the annual Fawkner Park Easter BBQ on Sunday 6 March to welcome home and congratulate the riders

- Cheering the riders while they're on Tour (details at <http://ridemaps.tourdetransplant.org.au>)

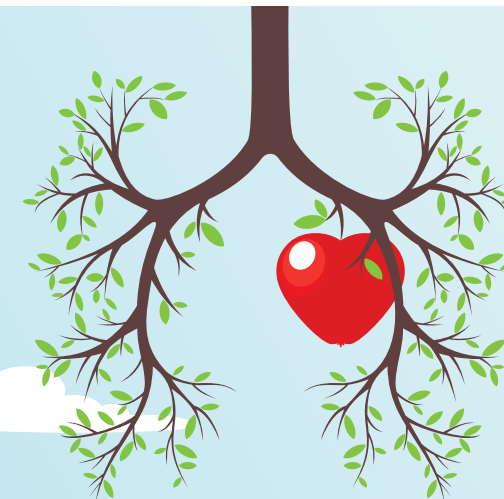
- Coming to the Geelong dinner. To help us meet our fundraising target we need to supplement our Tour fundraising with the proceeds of the dinner on Saturday 5 March at the Novotel. We will have some fantastic entertainment from Laura Loe, semi finalist singer on Australia's Got Talent, Phil Anderson OAM will tell some amazing stories from his career and we'll hear from an inspirational speaker. You will meet the Tour riders and possibly pick up one of the few priceless auction items on offer.

The \$65pp price includes welcome drink, food and all the entertainment. It would be great if you could purchase tickets and come along and join us. Even better if you were able to get family and or friends to come, buy a table of 10 and save \$50! For more details and to book online visit <http://geelongdinner.tourdetransplant.org.au>

If you live along the route of the Tour and would like to help us further, we are still keen to hear from you. Please contact Jon Rolfe on 0432 845662 or jon@hlttv.org.au



Tour de Transplant - Geelong Dinner



Join us for a special dinner to celebrate the 2016 TOUR DE TRANSPLANT

**Saturday 5 March 2016
Commences 6.30pm
Novotel Geelong, 10-14 Eastern Beach Road
Geelong, Victoria, 3220**

This event will honour the men and women who have cycled the 2016 Tour and help raise funds to support the Second Chance Accommodation Program.

Hear from Phil Anderson OAM about his riding achievements, meet the riders and pick up one of the few priceless auction items on offer. Enjoy a glass of wine and celebrate the success of the Tour.

The \$65pp price includes a three course meal and all entertainment.

Buy a table of 10 and save \$50 on the full price!

The event includes a raffle, a silent auction and a mystery game with excellent prizes up for grabs.

Visit <http://geelongdinner.tourdetransplant.org.au> to RSVP today!

For additional information, please contact Felicia Welstead on 0404 146 621 or email felicia@hlttv.org.au.



Living with Lung Transplantation: What is it like? Can we do better?

By Dr Chi Li
On behalf of the Living with Lung Transplantation study investigators

- Key Points**
- Lung transplantation at The Alfred improves quality of life and symptoms for patients with advanced lung diseases.
 - Patients and their carers would like more support both before and after transplantation
 - In response to these findings, the lung transplant program is now being redesigned to better meet our community's needs both now and into the future.

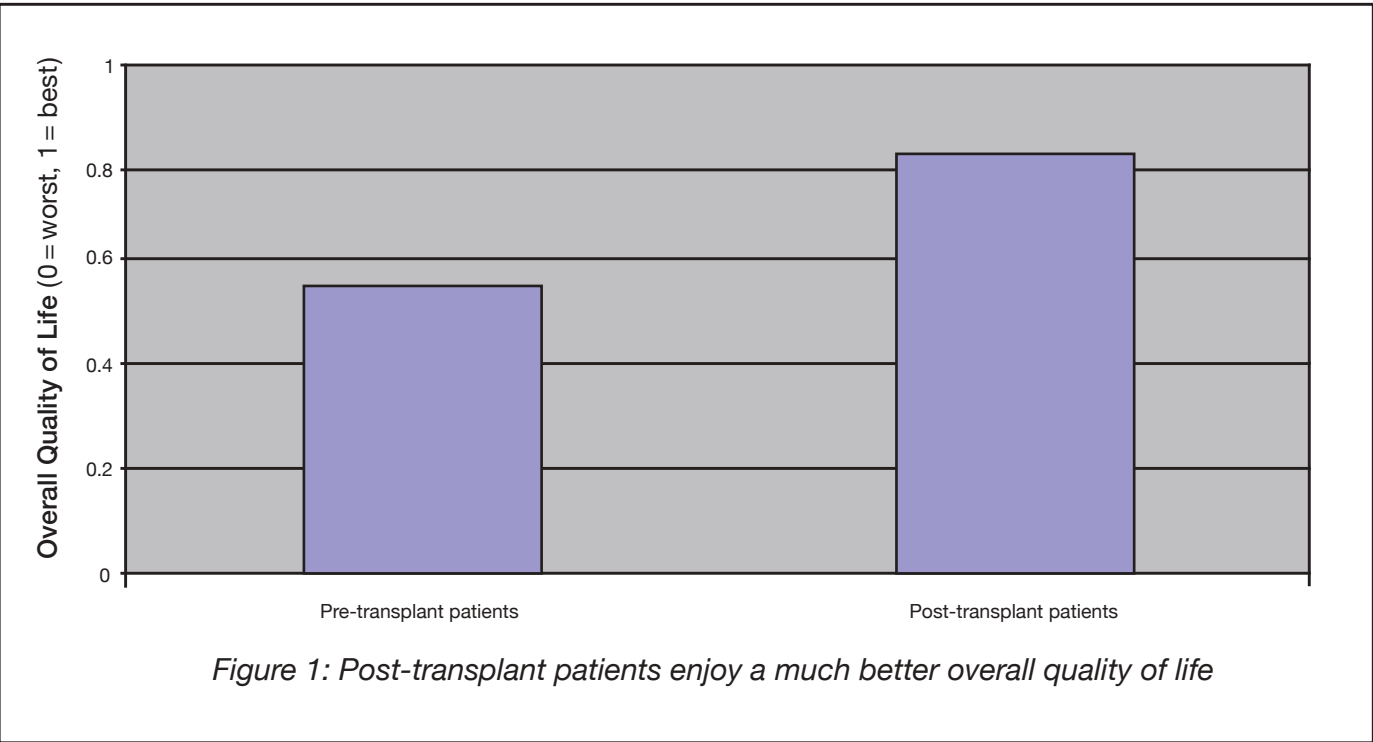
Lung transplantation is a complex and comprehensive treatment that is offered to increasing numbers of carefully selected patients with advanced lung diseases. The Lung Transplant Service at The Alfred is one of the largest and most experienced programs in the world. Over the last few years, not only have we been performing more transplants, our transplant patients are now living longer than ever before.

But are our transplant patients also living better? What is living with lung transplantation actually like for our patients and their families? And can we do better?

In order to answer these questions, we conducted the “Living with Lung Transplantation” study in 2015, in which we surveyed patients and their carers at different stages of lung transplantation, and asked them about their quality of life, symptoms and supportive care needs. Many of the readers of The Circulator are likely to have been part of this Australia-first study. We are now finalising our data analysis and would like to share with you what we have found so far.

Lung transplantation improves quality of life and symptoms

One of the key findings of our study is that patients report a much better quality of life and fewer symptoms (such as feeling short of breath or feeling tired) after transplantation. While this might sound obvious, it has actually never been studied in Australia before! In fact, transplant recipients at The Alfred enjoy a quality of life that is comparable to the rest of the Australian population. Interestingly (and perhaps surprisingly), transplantation does not appear to change their carer's quality of life.



More support is needed both before and after transplantation
The survey also revealed that patients and carers at The Alfred would like more support both before and after transplantation. While we might expect someone to need lots of help before transplantation (especially if they are living with a poor quality of life and lots of symptoms as we've just discussed), we might not have expected them to need much assistance after transplantation.

As it turns out, people want different things depending on where they are on the transplant journey. We also discovered that patients and carers often want help with different things. For example, pre-transplant patients would like more support with understanding what is happening with their health and treatment, as well as helping their family and friends cope with their illness, while their pre-transplant carers want more information about what to expect in the future, as well as more practical assistance at home. In contrast, post-transplant patients want more help with paying for their healthcare, while their carers would like more support with dealing with their own worries and finding time for themselves.

Can we do better?
Results from this study have many important implications. First of all, it provides a baseline or benchmark for future Australian studies in lung transplantation. From now on, not only can we measure if our patients are living longer – we can also gauge if they are living better. Secondly, now that we know what our patients and families would like more help with, we are keen to do better and have already started to redesign our program to address some of these needs. Thirdly, while we've always known that our patients and families are key members of the lung transplant team, this study has helped to give them a voice at the table. We would certainly love to do more of this if we can!

Finally, we would like to say a big thank you to everyone who has participated in and/or helped with the “Living with Lung Transplantation” study over the past twelve months. A more detailed study summary will soon be on its way to those who have requested it, and will also be available in lung transplant clinic for those who are interested.

If you have any questions about this study, want to find out about other studies we are doing, or (even better) would like to help us improve our service by becoming involved in our program redesign, please feel free to contact me by email at C.Li@Alfred.org.au or speak to any member of the lung transplant team.

Best wishes for the year ahead!

Transplant anniversaries - we wish you many more

We work hard to keep our database up to date, but if you know of any changes to anniversary announcements please contact our Membership Officer via membershipofficer@hlttv.org.au

February

Heart:

- Mark Brewer, 2008
- Margaret Neilson, 2009
- Barry Parsons, 1997
- John Winter, 1992

Lung/s:

- Alison Chapman, 2015
- Jeannett Collins, 2008
- Camille Condon, 2013
- Phyllis Cremona, 1994
- Ken Gain, 2004
- Debra Larchin, 2011
- Kirsten Larsen, 2003
- Frank Lineen, 2008
- Ronette Williams, 2015

March

Heart:

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

Lungs:

- Nola Barry, 2011
- Camille Condon, 2013
- Judi Groves, 2012
- Heather Hill, 2006
- Toni Miles-Bennett, 2011
- Suellen Pettersen, 2002
- Yehia Ragheb, 2015
- Jon Rolfe, 2009
- Betty Sammartino, 2011
- Lois Scott, 2012
- Robyn Scott, 2015
- Vicky Yfantis-Cocossis, 2013

April

Heart:

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

Lung/s:

- Jeff Campbell, 2008
- Ian Francis, 2010
- Gwen Ledwidge, 2009
- Bruce Vernon, 2015
- Andrew Weybury, 2010

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.

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.



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.hlttv.org.au/> and follow the 'Membership' links.



Heart and Lung Transplant
Trust (Vic) Inc
Bringing the Alfred transplant family together
www.hlttv.org.au

2016 EASTER BBQ

SUNDAY MARCH 6TH 12PM

at Fawkner Park
(opposite the main entrance to the Alfred)

COME ALONG AND WELCOME BACK OUR MAGNIFICENT 2016 TOUR DE TRANSPLANT RIDERS AND SUPPORT CREW

The Easter BBQ is a great social event for pre and post transplant patients, families, carers and friends. BBQ and drinks are provided (inc vegetarian options) with great raffle prizes on offer and an easter egg hunt for the kiddies

BYO Chairs and Tables (and shelter in case of rain)

To find out more contact Jeff - events@hlttv.org.au 0425 782 830

or Martina - martina@hlttv.org.au 0409 957 492

We truly look forward to seeing you there

