



the Circulator

Third Quarter | 2013 | Issue No. 74

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



The Rotary Club of Nathalia takes on management of Heart to Heart House

See our story on page 4 about this amazing property, providing a place to rest, recuperate and recover by the River Murray (Photo courtesy Ian Stubber).

In this edition

President's message.....2	Fun with fundraising.....8	Transplant Anniversaries..15
Editors message.....16	Tour de Transplant update.....10	Become a member.....19
New website launched.....3	Community Corner.....12	Christmas BBQ.....back page
Respite House under new management.....4	Clinic News.....14	
Meet our first Second Chance Guest.....6	AGM.....16	



Anne Griffiths retires after five decades of service to the transplant community (page 14)



President's message - Spring 2013

Since its beginnings in the 1990s the Heart & Lung Transplant Trust (Victoria) Inc has had as its vision to pursue a bright and active future for all those involved with or in need of a heart or lung transplant.

This driving passion has led us to commence the biggest undertaking in our history: to provide accommodation for all country and interstate patients and carers during their three month minimum compulsory post transplant rehabilitation at The Alfred.

The Second Chance Accommodation Program commenced in May 2012 with two apartments at Park Regis Griffin Suites St Kilda Rd.

Park Regis becomes the home away from home for the patient and carer during this very stressful period.

We realise that two apartments in no way satisfies the demand for accommodation for all patients who are living away from home post transplant.

At the time this newsletter is being produced, we are proud to announce our success in securing a third apartment.

We need eight apartments and that is what we are striving for.

We are engaged on the largest fund raising campaign in our history.

I am pleased to announce that we have entered into a fund raising partnership agreement with StayWell Hospitality Group which is the parent company of Park Regis.

Jon Rolfe, our secretary, and I attended the annual dinner in Melbourne of the StayWell group in July as honoured

guests.

The dinner was attended by all senior executives of StayWell. Most of the general managers from the many properties in the group were also present.

There were managers from all over Australia, from Singapore, China, India, Dubai and the United Kingdom.

Jon was invited to speak at the dinner and recount his moving and courageous transplant journey from the age of four when he was diagnosed with cystic fibrosis and not expected to live past eight to his double lung transplant four years ago at around 40, and his exciting life after that great gift of transplant.

As I watched the audience of hardened business people I was struck by how moved they were by his story.

With only a few last details to be decided HLTTV will be StayWell's major philanthropic partner.

We are deeply indebted to CEO Simon Wan and his team in the Group and both StayWell and HLTTV are thrilled to be commencing this exciting journey.

The partnership with StayWell is a most important milestone in our fund raising quest but it is only one avenue that we are pursuing.

We have planned for March 2014 the Tour de Transplant, a cycling challenge around Victoria led by Australian cycling icon, Phil Anderson.

In 2015, we will follow up with the Gallipoli 100 Year Swim as part of the centenary of Gallipoli a swim from Europe to Asia

across the Dardanelles Strait a distance of some 4.5 km.

I encourage you to find out more about these events on our newly updated website (www.hlttv.org.au).

I sincerely thank all members for their continued support in our mission.

Our committee remains dedicated to providing the best possible outcomes for the many members of the "Alfred Transplant Family".

Good health to you and yours.

David Hayne
President, HLTTV

HLTTV contacts

President | David Hayne

Ph: 0418 148 919

president@hlttv.org.au

Vice president | Rom Konieczny

Ph: 0418 514 227

vicepresident@hlttv.org.au

Secretary | Jon Rolfe

Ph: 0432 845 662

secretary@hlttv.org.au

Treasurer | Jane Cooper

Ph: 0414 447 624

treasurer@hlttv.org.au

Membership officer | Louisa Walsh

Ph: 0427 509 042

membershipofficer@hlttv.org.au

Patient support | John Bisiach

Ph: 0427 455 482

patientsupport@hlttv.org.au

HLTTV events | Jeff Campbell

Ph: 0400 031 698

events@hlttv.org.au

Partnership the heart and soul of new website



An interactive events calendar, and dedicated event pages make it easy to stay connected.

Our new website features fully secure payment options for membership.

Our new 'members only' area features many valuable resources for those on the transplant journey.

Innovative partnerships and a shared vision have seen the incredible gift of a new website www.hlttv.org.au for the Heart and Lung Transplant Trust, Vic (HLTTV).

HLTTV President, David Hayne, is thrilled at what has been achieved through the goodwill, talent and technical expertise of two key partners.

"With a growing membership, and ever-increasing number of people on the journey to transplant, our volunteer committee knew we needed a different approach to the way we source donations and support for those in The Alfred Transplant Family," said David.

"In 2012, we made the decision to seek professional support from Greg at Campitelli Consultancy to help guide us with a more

strategic approach for our Second Chance Accommodation Program. Through his networks, Greg was able to connect us with JWAM, a Geelong based company who have donated their time, resources and expertise to build a much needed new website.

"Apart from looking much more professional, the new website www.hlttv.org.au, reduces the administrative load for our volunteers by providing online options for membership, donations and an ever-evolving 'members only' section. Members will have access to the latest resources and news, one-on-one support and fitness grants," he said.

Visit the website at www.hlttv.org.au for more information about who we are and what we do for those on the transplant journey.

Our site still has its 'training wheels' on, so we'd love your feedback.

***You can use the 'contact us' form on the site, or
email: webmaster@hlttv.org.au***

Patients the winners as new management begins at popular Heart to Heart Respite House

The History - Bill's Vision

Victoria's Barmah Township situated right on the Murray River is a very special place to Bill Vickers.

As a transplant patient (heart, 2003) Bill knows all too well the stresses for patients and their families and understood that having somewhere peaceful to relax or recover prior to or after their transplant was important.

It was also important to have a place close enough to medical treatment facilities and the air ambulance. Echuca was close by, and so the huge task began.

Bill and his wife Glenys donated land next to their property in Barmah using a peppercorn sale amount, necessary to make it legal.

A Committee was formed for the project and there was wonderful support from businesses, organisations and individuals.



Peace and tranquility in Barmah.



Bill and Glenys Vickers - the driving forces behind Heart to Heart House.

Bill managed construction of the house, and ensured careful consideration was given to house planning, garden design and furniture and fittings selection.

There was over four years of fundraising, beautifying the land and building the house.

Community support was evident at the official opening in 2009, with more than 400 people present.

These were people who had been involved in the Committee and the many supporters.

The Alfred's Dr Peter Bergin and Heart Transplant Nurse Sue Tamblyn attended, as well as the local MLA represented by Paul Weller.

Since the official opening further improvements have been made, with the addition of a carport providing extra protection and shade.

The Next Phase - The Rotary Club of Nathalia takes on the Management Committee role

As some members of the Heart to Heart Committee are getting on in age, and the niggles of illness are making themselves felt, it was decided to look for a suitable organisation to take over the ownership and running of the House.

In July 2013 the Rotary Club of Nathalia was named as the new owner of Heart to Heart.

The Rotary Club had already been involved and was thrilled at being able to continue this very worthwhile cause without any interruption to those using the house.

Even the name stays the same: HEART TO HEART RESPITE HOUSE INC.

The Rotary Club of Nathalia will be there for many generations to come, and will

Find out more about Heart to Heart Respite House by visiting the website at www.hearttoheart.org.au or by visiting the 'about us' tab on the HLTTV website

Patients the winners at Heart to Heart House (cont.)

run the House to the same high standards held by the previous committee.

While the first committee secretary, Kevin Williams, also doubled as the booking officer, today there are two booking officers; Martina Appelman (0409 957 492) and Laraine Anderson (0418 599 745).

From Bill Vickers, Ex-President of Heart to Heart Respite House Inc.

'It was a pleasure to be associated with the Heart to Heart project.

I want to sincerely thank everyone who has helped over the years, and I wish the Rotary Club of Nathalia all the best with this facility.

I know that it could not be in better hands.'



A celebration and thank-you dinner was held in July 2013 in conjunction with the AGM and handing over to the Rotary Club of Nathalia.

Thank you so much Bill and Glenys

From all of those who have enjoyed their time at the Heart to Heart Respite House at Barmah (around 55 transplantees and over 150 of their friends or families) and the many who will enjoy this in the future, we say a big thank you for your dedication to achieving this wonderful opportunity to have somewhere to relax.

Heart to Heart house handed over to Rotary

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Barmah's respite house for people who have had heart and lung surgery has had a change of management.



Takeover: Bill Vickers has handed over the running and maintenance of the Heart to Heart respite house at Barmah to Nathalia Rotary Club, including Rotary treasurer Ken Gunn, new Heart to Heart president Allan Locke and Rotary president John Attwood.

A small committee has run the Heart to Heart respite house since it opened in 2009 as a place for people who have heart or lung surgery

Mr Vickers came up with the idea of the heart house while recovering from his own heart transplant in 2003.

He donated the land at the back of his own home for a house to be built and a committee set about raising the money needed for it to be built.

Mr Vickers said he thought it was now time to hand over the running of the house to a group.

"I was fairly crook in January and it prompted me to get the heart house into other hands," he said.

"It was hard to relinquish it, but it had to be done.

"It's going to continue now, that's the good thing.

"Rotary, their members will change, but Rotary will be there forever (to run it)."

New Rotary Heart to Heart president Allan Locke, who took over the role on Friday, paid tribute to Mr Vickers for setting up and running the house until now.

"He's done a marvellous job. It's a credit to him," Mr Locke said.

"It's a great community project and it's good for Nathalia Rotary to have been given the honour to have taken over the house."

Mr Locke, who has personally had a friend stay at his home after heart surgery, said having somewhere to relax was the key to recovery after surgery.



The change was featured in local paper, The Riverine Herald.

Thank you for being such wonderful hosts and we encourage all those in the Alfred Transplant Family to support Heart to Heart House into the future.

Bookings for Heart to Heart House can be made through either of the friendly booking officers: Martina Appelman (0409 957 492) or Lorraine Anderson (0408 599 745).

First guest of Second Chance Accommodation program learns to 'go with the flow'

Learning to go with the flow – a journey to double lung transplant through pulmonary arterial hypertension (story generously shared by Maurice Reid and his wife Denise with Belinda MacLeod-Smith).

When I spoke to Maurice Reid, he was enjoying life in a way he didn't think would be possible a few years ago. Sitting on the verandah of his Eildon home in rural northeastern Victoria enjoying feeding the rosellas is a far cry from his life some 18 months ago.

Maurice received a double lung transplant at the Alfred on March 25, 2012, and subsequently became the very first country transplant recipient to use our Second Chance Accommodation program.

There are many different journeys to transplant – some are sudden and unexpected and some arrive after years of managing complex chronic illnesses. Maurice's journey had a little bit of both elements.

Up until early 2009, Maurice had been incredibly active and busy with his Eildon based cabinet making business, supporting his wife in her business and coaching the local tennis team.

Eildon, around two hours from Melbourne, is part of the Shire of Murrundindi that was catastrophically affected by the Black Saturday Bush Fires in February 2009.

It was after those terrible

fires that 51-year-old Maurice noticed a constant burning sensation in his lungs, and a gradual decline in his health that included breathlessness and extreme fatigue.

His symptoms were quite debilitating, and while he was unable to continue working, a lack of specific diagnosis meant he was also unable to qualify or receive benefits, creating significant financial stress.

By the end of 2009, Maurice had started experiencing heart attacks as a result of the pressure of his lungs working against his heart.

It wasn't until 2010 that a cardiologist consultation at The Austin with Dr Mark Horrigan, gave him the diagnosis that he had a rare lung disease – pulmonary arterial hypertension (PAH).

PAH is a disease that causes progressive obstruction of blood flow through the lungs. Unfortunately being put on the right course of medication only helped Maurice for around eighteen months as opposed to the hoped for 3-5 years.

A referral to Dr Helen Whitford, a leading specialist in PAH was a game-changer for Maurice, as was connecting with Professor Greg Snell and the cardio-thoracic team at The Alfred in 2011.

Unfortunately medication was still unable to provide a solution, and with Maurice incredibly unwell he had the



Taking pleasure in each day as it comes - good advice for us all.

difficult job faced by many on the transplant journey of getting his affairs in order and saying goodbye to family and friends.

With a rare blood group and worsening health, the decision was made to go ahead with transplant using what is referred to as a 'compromised' donor.

This type of transplant means that the match is not the ideal match, but still presents a better chance of survival than no transplant at all.

The nature of transplant and recovery is different for everyone, and with complications post-transplant, Maurice and his wife ended up staying in Melbourne for more than six months to support his recovery.

While the emotional pressure and stress of the situation was huge, financial pressure certainly adds to the load carried by transplant

First guest (cont)

recipients, their families and carers.

It's exactly this kind of situation that the Second Chance Accommodation Program was developed for. Subsidised accommodation is just one way to support regional and interstate transplant recipients at a time when they really do have better things to think about.

After 'dying' numerous times, and surviving only by the virtue of bypass technology, life still has many frustrations and physical limitations, especially considering so much happened in so few years.

From not being able to get out of bed and being wheelchair dependent, he loves that he can get outside to help a neighbour feed cattle, and hopes one day to get back to tennis coaching.

Maurice appreciates what he has now more than ever, and at 55, he's grateful to be alive and just go with the flow.

Home is where the heart is...

The Heart and Lung Transplant Trust (Victoria) accommodation program strives to provide affordable accommodation for heart and lung transplant recipients and their carers.

This program would not exist without the invaluable support of Park Regis Griffin Suites, Melbourne.

Thank you.

Special thanks are also extended to the Rotary Club of Williamstown for their generous support.

www.hlppv.org.au

PARK REGIS
GRIFFIN SUITES • MELBOURNE

Park Regis Griffin Suites and Staywell continue as valued program partners

Since May 2012, HLTTV have been thrilled to partner with the Park Regis Griffin Suites to provide affordable, accessible and practical accommodation solutions for regional transplant recipients.

Situated between Melbourne's city centre and popular 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.

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



contact the Park Regis for available discount rates, and show them the same kind of support they show us.

Park Regis Griffin Suites
Phone | (03) 8530 1800
Location | 604 St Kilda Road, Melbourne
Email | griffin@parkregishotels.com
Web | <http://www.staywell.group.com/hotels/melbourne/park-regis-griffin-suites>

Donations to the Heart and Lung Transplant Trust (Victoria) are fully tax deductible and super easy!

Simply visit <http://www.givenow.com.au/hlppv> so we can keep helping those on the transplant journey.



Putting the 'fun' into fundraising!



A very full house for the HLTTV Trivia Night fundraiser

The Heart Lung Transplant Trust of Victoria held a trivia night on the June 29 at St Silas Church hall in Albert Park. The venue was provided thanks to the generosity of St Silas Parish and the Vicar Ray McInnes.

There was a full house in attendance and close to \$2,500 worth of items were donated as prizes for the night. Attendees were kept entertained throughout by quiz master Jon Rolfe, brain teasers, a silent auction and a paper plane competition.

The Trivia Night raised close to \$2,500 for the Second Chance Accommodation Program.

HLTTV would like to extend



Event manager Claire Stubber with Gaylynn Pinniger.

a sincere thank you to our generous sponsors and donors:

- A Little Vintage: Jennie Walker
- Computer Mind Australia: David Ash
- Curly Pops: Camille Condon
- Glenfield Cottage
- Jay Hynes Photography
- Leaf and Petal: Karen Lynch
- Len Hain
- Little Circus Design: Madeline Stamer
- Maureen May
- One Busy Sloth: Jo Chan-Woerlein
- Polly Pratt: Anna Boyd-Dunlop
- Raspberry Rainbow: Cat Tranter
- Red Riding Hood Photographic Images: Evelyn Hood
- Retrofied: Leanne Murdoch
- Rhyley Designs: Natalie Roelvink
- RMAX Rigid Cellular Plastics
- Sayraphim Lothian Public Artist
- Sean Jennings
- Snap Happy Ian: Ian Stubber
- The China Hutch: Michelle Yates
- The Flower Garden: Anja (10 Years Old)
- The Silver Forge: Ruthie Gray
- Too Cute by Farrah: Farrah Tate
- Victoria Mason Jewellery
- Weddings With Care: David Ash



Would you like to support Heart and Lung Transplant Trust Victoria but aren't sure where to start?

HLTTV can help you on your way with at least **13** great fundraising ideas!

Check our website under the **'fundraising'** tab.

It doesn't matter whether you're an individual, group or business - with an interest in supporting those fortunate enough to gain a second chance at life, your fundraising can be a great success.

HLTTV can provide useful tips, advice and support for your fundraising event or activity. For example, we can provide tax deductible receipts to donors. To find our more, email: secretary@hlttv.org.au



Jon Rolfe and Louisa Walsh getting into the spirit of things.

Putting the 'fun' into fundraising!

Theatre night fundraiser supports Second Chance Accommodation Program

Double lung transplant recipient Kathryn Wright with sisters Claire and Maree were just some of the fifty-five attendees supporting the fundraiser for the Accommodation Program at the Opening Night of Heidelberg Theatre Company's production of 'One Flew Over the Cuckoo's Nest'.

The play is quite confronting, and those attending praised the actors for their excellent performances.

Gaylynn Pinniger would like to thank all those who supported this fundraising event, with some \$825 raised with ticket sales.



Below: Kathryn Wright (middle) with sisters Claire and Maree.



Martina helps out during the Clover Cottage Fundraiser

Dinner for 103 - what a way to celebrate your 4th Transplant Anniversary!

Martina Appelman (double lung transplant) combined this milestone with a wonderful evening on September 11 at Clover Cottage at Berwick to raise funds to go towards supporting HLTTV's Accommodation Program through the Tour de Transplant cycling event planned for March 2014.

The evening began with entertainment by the Mary Knoll singers (Martina is a choir member) followed by an auction conducted by Paul Dabb from Barry Plant.

Items kindly donated for the auction included a Richmond Football Club Guernsey signed by the Leadership Team,

Global Zone Alarm system, accommodation at Erin View House Bed & Breakfast Mansfield (2 nights), one night's accommodation at the Park Regis Griffin Suites, a painting thanks to Beaconsfield Framing, and hampers from Hair Club Melbourne and Miris spices and sauces. Vouchers were donated by 81 Wine Bar (high tea for two) and Clover Cottage (dinner for two).

An amazing \$3,600 was raised on the night thanks to Martina's effort and the support of her many guests and generous sponsors.

Event update Hottie Challenge

In our last edition, we featured the Hottie Challenge – a fundraising auction featuring incredibly creative hot water bottle covers.

All funds raised are donated to the Margaret Pratt Foundation Heart and Lung Transplant Trust for research into chronic rejection. Generously hosted by Robyn and Prue from Open Drawer in Hartwell, the Challenge raised a scorching \$3400.

Making the Tour de Transplant 2014 a huge success

Let's make it a huge success

By the time that you receive this edition of The Circulator we will be just 6 months away from starting to realise our dream.

HLTTV will be staging Tour de Transplant as a major fundraiser for our Second Chance Accommodation Program.

Through the Tour, we plan to raise sufficient funds to put us well down the path to accommodate recipients and their carer during their post-transplant recovery period.

Our dream is extraordinary

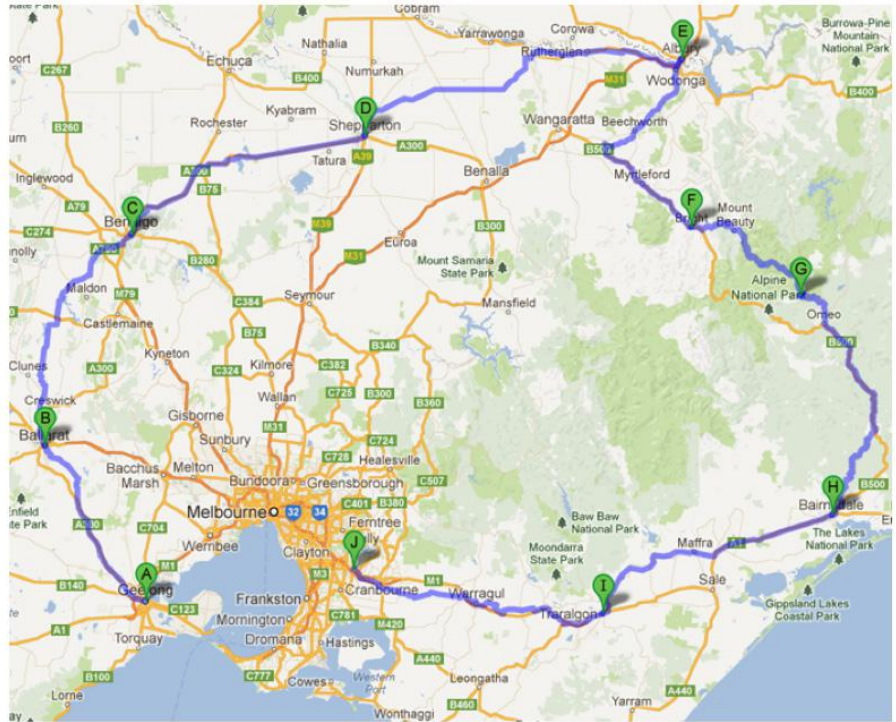
Our program has the power to deliver an easier road for every Victorian regional and interstate transplant family facing this life-changing event.

It eases their immediate financial burden and allows them to focus on themselves, their recovery and to the next stage of their lives.

The impact is significant

It affects one in every two transplant families and with the right funding we expect to be able to help 100 families over next three years.

The overall impact is much bigger with each family we help because we also impact the many other people they know.



A remarkable cycling challenge of 1100km, representing one kilometre for each past transplant recipient.

The Tour

We intend to raise a significant sum through the Tour, a remarkable cycling challenge of 1100km, symbolising one kilometre for each past Victorian heart or lung transplant recipient and this money is essential to secure the further accommodation necessary to meet the demand.

Tour de Transplant is being led by Phil Anderson OAM, an Australian cycling icon and indeed the first Australian ever to wear a yellow jersey as the race leader during the Tour de France (see *Phil's message on the opposite page*).

You can also browse our exciting new website <http://www.hlttv.org.au/> for more detailed information including the route and details on how to register an expression of interest.

Cycle with a champion

The Tour is not only a great physical challenge but a unique opportunity to ride alongside and get to know a truly great Australian cyclist.

At each overnight stop on the route a sportsman's night will be organised where guests will sit down to a meal and hear Phil Anderson share some of his insights .

It will be a wonderful opportunity to listen first hand to this sporting legend and tales he has to tell about



Making the Tour de Transplant 2014 a huge success

the Tour de France, his years as a professional cyclist and his experiences at the Commonwealth games

Tour de Chat

We have also approached DonateLife to partner with us in a parallel event to take advantage of the publicity created by the Tour de Transplant.

We believe the Tour will maximise the opportunity to talk about the need for Australians to discover, decide and discuss organ donation.

Our event will take place shortly after DonateLife Week in 2014 and we believe that this is a wonderful opportunity to spread the word about organ donation and to raise awareness and discuss the issues in conjunction with regionally based Donate Life staff.



How you can help

Riders

We have limited entries to 25 participants and while places are filling we need your help to make sure we maximise numbers.

We ask you to speak to friends, relatives, acquaintances and work colleagues who are keen cyclists to encourage them to sign up and take part in this unique event.

Sponsorship

We have a number of very attractive sponsorship opportunities for businesses to be associated with the Tour.

These opportunities range from specific sponsorship, tailored to suit which may include rider participation, to provision of support from ranging from donations to goods and services.

Think about contacts you may have in the business world who may welcome the opportunity to support

this event and benefit through significant exposure throughout rural Victoria.

Assistance

We have appointed as our local ambassadors those from among you in each of these regional towns who have travelled the transplant journey and they are already busy contacting local people and organisations of influence.

They are our 'Local Champions' and will co-ordinate local celebrations and events as the Tour de Transplant and Tour de Chat arrive.

They will welcome help in terms of person-power, goods and services.

If you'd like to get involved, or need further information or support please phone David on 0418 148 919 or email: president@hlttv.org.au

To register your interest in the Tour de Transplant, you can also visit the dedicated page on our website.

Message from Phil Anderson, OAM

"This program is a fantastic initiative and I'm proud to be leading the inaugural Tour de Transplant Challenge to assist in fundraising for this cause.

Currently demand for support accommodation is outstripping supply and our goal will be to raise sufficient funds to increase the availability of support accommodation for more transplant recipients and their families to stay together during this difficult post-operative period.

This is a wonderful initiative and I will ensure the participants work very hard on their quest to ride 1,100km through rural Victoria. 1,100km for 1,100 heart and lung transplant recipients here in Victoria.

I want this to be an enjoyable and memorable experience for all concerned."

Community corner

Spring clean your diet with a tasty beef stir fry

Intrepid Circulator team member Claire has a great eye for recipes, and has shared this fantastic stir fry that'll boost your vegie intake for spring.

This is a very quick recipe once the vegetables and beef have been prepared. It's also very adaptable, simply playing with the quantities of soy sauce, lemon juice, garlic, chillies and Shaoxing wine makes it easy to adjust to your particular taste.

Ingredients

- 5 cups of assorted vegetables e.g. broccoli, red capsicum, choy sum, snow peas
 - 1 bulb of garlic
 - 2 long red chillies
 - Juice of 1 lemon
 - 1 thumb-sized piece of ginger
 - 1 brown onion, diced
 - 1 tablespoon soy sauce
 - 2 tablespoons Shaoxing wine (Chinese Rice Wine) or dry sherry
 - 250 grams rump steak, trimmed of all visible fat
 - 1 tablespoon cornflour
 - 1 ½ tablespoons water
1. Prepare vegetables by washing and chopping into similar sized pieces, if using vegetables such as choy sum and bok choy, remove leaves and dice stems. Slice leaves and put aside.
 2. Peel and slice ginger and garlic.
 3. Roughly chop the ginger, ½ the garlic and the chillies. Place in a small food processor and grind to a smooth paste.
 4. Mince the remaining garlic and set aside
 5. Thinly slice the rump steak, to get thinner slices you can place the steak into the freezer for an hour or two before you need it.
 6. Heat a wok to smoking point, add ½ a teaspoon of oil or some oil spray and add the onions. Cook until translucent.
 7. Add the chilli, garlic and ginger paste and cook for about 30 seconds or until fragrant.
 8. Add the vegetables to the pan together with the soy sauce and the Shaoxing wine or sherry. Cook for two minutes then remove from wok and set aside.
 9. Bring the wok back to smoking point, add a little more oil if needed and then add half the steak. Brown, add some of the minced garlic then remove from wok. Repeat with remaining steak but do not remove.
 10. Add vegetables back to wok. If using, add choy sum leaves at this stage
 11. Make a paste with the cornflour and water, add to the wok and stir until the sauce thickens, remove from wok.
 12. Serve with rice

Do Good Stitches Quilt



During August, Kelina Attard and Bronwyn Levvey took receipt of a quilt donated by a group called Do Good Stitches.

The quilt is intended for a transplant recipient who is in need of a bit of extra TLC.

Do Good Stitches describes their group as a virtual quilting bee.

Members join through the photo sharing site *flickr* and then stitch individual quilt panels which then get sent to one person who sews all the panels together to form the quilt.

Every month the group assembles a quilt for that month's chosen charity.

The theme for the quilt donated to the Heart Lung Transplant Trust (Victoria) was 'imperfect houses'.

You can view the impressive array of quilts and quilt panels made by the group at:

<http://www.flickr.com/groups/dogoodstitches/pool/>



Community corner

Spring in Melbourne

Recent double lung transplant recipient and all-round inspiration Camille Condon (of Curly Pops fame) has some great advice to put the spring back into your step.

After a long cold winter, Spring is the perfect time to get out and enjoy yourself.

Physical and mental wellbeing is very important whether you're pre or post transplant.

Getting out and about is the perfect way to exercise both body and mind (and it will keep the physios happy too!)

If you're a bike rider, there are multitudes of great places to ride around Melbourne.

As a bonus, you can use all that riding as training for the Tour de Transplant!

Bicycle Victoria has a website packed with everything you need to know.

If you're more of a walker, there are beautiful parks and gardens all over Melbourne, along with lots of organised tours.

There's even one dedicated to Chocoholics!

Have you been to the zoo? Zoos Victoria run three very different zoos – Melbourne Zoo, Healesville Sanctuary, and Werribee Open Range Zoo.

All three have fantastic walking tracks, but if you're pre-transplant you may prefer a visit to the Werribee Open Range Zoo.

If you can't make it around the walking tracks, they have a

wonderful bus trip that takes you around all of the open plains to see the animals.

If you're not the outdoorsy type, Melbourne has many wonderful galleries.

The National Gallery of Victoria (NGV) has a running calendar of events and there's always something special to see. For something more modern, check out ACMI at Federation Square.

There are so many events happening in Spring – visit these great websites to help put the spring back into your step!

- <http://www.bicyclenetwork.com.au>
- <http://www.victoriawalks.org.au/Melbourne/>
- <http://www.thatsmelbourne.com.au>
- <http://zoo.org.au/>
- <http://www.ngv.vic.gov.au/>
- <http://www.acmi.net.au/>

We'd love to hear from you if you attend any of the following fun events - drop us a line, or send us a picture to share.

3 Sep – 24 Nov
Spring Racing Carnival

20 Oct
Around The Bay - Ride distances from 20km – 250km

27 Oct
Cystic Fibrosis Vic Great Strides Walk (around the tan) 4km walk/run or 8km run

11 Nov
Remembrance Day

17 Nov
City2Sea Melbourne - 14km Run

24 Nov
The Colour Run – 5km

Remember to contact us via the website with any events you'd like to share.

Email: circulator@hlttv.org.au

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.

Clinic news

News from the Third Floor

Cardio Thoracic team member Laurie Keown was kind enough to take some time to answer a few questions.

How many staff currently work within the Clinic?

Currently we have two nursing staff in clinic, two nursing staff in the ventricular assist device (VAD) program & two nursing staff that manage our waiting lists and transplant coordination.

I'd also like to give Anne Griffiths a mention (*see story next page*). Anne retired on the 30 August after 52 years of working at the Alfred.

She started as transplant Coordinator in 1988 when the program began with Don Esmore (surgeon) and Jane Harris (social worker).

An outstanding record of service to the transplant community!

Are there any recent developments you'd like to share with Circulator readers?

We have recently set up a new transition program for patients moving their care across from the Royal Childrens Hospital.

We will have dedicated clinics for these patients for the first 12 months working closely with the RCH staff and Gillian Coult (our social worker).

Georgia and Gill have done a lot of work to set up the program

and we hope this will make that (sometimes) difficult transition smoother for the younger patients.

Any health recommendations/reminders for pre or post transplant patients (in the context of upcoming allergy season/immunizations etc)

We'd like to remind all patients that they should have had two influenza vaccinations this year. They are given 6 weeks apart (the second acts as a booster).

A reminder to be sure to bring any scripts you may need to clinic with you, and if you find you are running low on a script or medication, the best time to contact clinic is when you reach your last repeat.

Lastly, make the most of the spring sunshine! Keep as active and as fit as you can.

News from the Fifth Floor

Dr. Greg Snell, Lung Transplant Physician was also kind enough to provide the following update:

A solid year so far with 47 lung transplants and 15 heart transplants with some huge successes.

We have also seen a couple of previous lung transplant patients undergo successful kidney transplants.

A new Director of Cardiothoracic and Transplant Surgery has started. Professor David McGiffin.

Prof McGiffin has been working in the US for a decade or so, having previously done heart transplants in Brisbane.

We look forward to his new thoughts, vision and extra surgical skills.

We do seem to be seeing a little bit of spring asthma and rhinitis, and the odd puff of ventolin or a simple antihistamine are quite safe.

Warmer weather is a reminder to point out the need to make sure the 'slip-slop-slap' message is remembered.

This is particularly an important issue for patients on Vfend (voriconazole), which is an antifungal medicine we now associate with potential sun-related significant complications.



Visit www.sunsmart.com.au to see the latest UV alerts.

The Circulator team extends our warmest thanks to all the Alfred Staff who help those on their transplant journey, and make the time to share information with our readers.

Anne Griffiths retires after five decades of service to the transplant community



Anne Griffiths recently retired after an amazing 52 year career at The Alfred.

Anne started at The Alfred as a 'Pinky' (someone who cleaned up, folded linen and ran messages) as she was too young to be a Nurse.

During her long career at The Alfred Anne worked in different areas and was involved in a variety of important and interesting roles.

Of course we all know Anne from her role as Transplant Co-ordinator.

Anne started in the Transplant Unit in December 1988 - before Prof Esmore was appointed. He arrived in the second week of February 1989 and the first heart transplant was the following week.

Anne mentioned that she actually prepared the intensive care area at The Alfred for Australia's second heart transplant in 1968.

It was the 75th in the world.

Anne said that potential transplant recipients responded to her call in many different ways.

Some were very nervous, others excited, some even just said 'I knew it was you calling'.

Only two have ever said they did not want the transplant.

Anne has enjoyed her time working with the Transplant Service. At times it has been very demanding, but she feels it has been a privilege to be able to contribute.

Jamie Hobson originally from England has been appointed as Anne's replacement (with a new title of Transplant Liaison Nurse Coordinator).

Jamie has a number of years experience in cardiac and intensive care and more recently was working in the Heart Transplant Clinic.

Aimee Henrickesen has been appointed as Jamie's offside. Aimee is from New Zealand and after a number of years in ICU in Australia and England she has come to the position via working in the Clinic as well.

Anne feels very confident that she is leaving the position in good hands.

On behalf of HLTTV and all those who have share their journey with Anne, we send our thanks and very best wishes.

ADVANCE CARE PLANNING

Keep control

Planning ahead for your future healthcare

Planning ahead for peace of mind

Clinic staff would like to share information about an excellent free service to patients of Alfred Health (or those living in the Cities of Bayside, Glen Eira, Port Phillip and Stonnington.)

Alfred Health offers an Advance Care Planning service that can help you organise things such as:

- Medical Enduring Power of Attorney
- Advance Care Directives

For more information

Phone: 9076 6642

Email: advancecareplanning@alfred.org.au

Website: <http://www.alfredhealth.org.au>

AlfredHealth

Editor's Spring message

Welcome to the third quarter 'Spring' edition of the Circulator.

Spring is traditionally known as that lovely time of year when we start to feel some warmth after the chilly winter months, and new growth can be seen springing up all around us.

So it's apt that it's this quarter we launch an updated website, and applaud the huge growth in community fundraising that's taken place recently.

All members would have received contact from David Hayne (President) outlining the many different

and fun options that can be considered if you feel up to the satisfying challenge fundraising.

We've had everything from primary school dress ups, quiz nights, theatre productions and dinners.

We've dedicated quite a few pages (see page 8) to feature these events and the people that host them.

Of course, our highest priority is to support all those on the transplant journey and I was lucky enough this month to interview the very first transplant recipient to use our Second Chance Accommodation Program in March, 2012 (see opposite page...)

Notice of Annual General Meeting and proxy form

The Annual General Meeting will be held on Tuesday 12 November 2013 at 7.30pm in the 5th Floor Seminar Room, The Alfred. The ordinary business of the annual general meeting shall be:

- (a) to confirm the minutes of the previous annual general meeting and of any general meeting held since that meeting; and
- (b) to receive from the committee reports upon the transactions of HLTTV during the last preceding financial year; and
- (c) to elect officers of HLTTV and the ordinary members of the committee; and
- (d) to receive and consider the annual report prepared by the HLTTV in accordance with section 94(1) of the Associations Incorporation Reform Act 1982.

The minutes and Annual Report and Accounts to be considered are available from the Secretary on request or can be found on the website at www.hlttv.org.au

Any member intending to bring any other business before a meeting must notify the Secretary in writing, or by email to secretary@hlttv.org.au no later than 10 October 2013.

Each member is entitled to appoint another member as a proxy by notice given to the Secretary no later than 24 hours before the time of the meeting, or handed to the Secretary by the time of the meeting. Proxy form is attached to this notice.

Nominations of candidates for election as officers of HLTTV or as ordinary members of the committee must be:

- (a) made in writing, signed by two members of the HLTTV and accompanied by the written consent of the candidate (which may be endorsed on the form of nomination); and delivered to the Secretary not less than 7 days before the annual general meeting
- (b) a candidate may only be nominated for one office, or as an ordinary member of the committee, prior to the annual general meeting.
- (c) if insufficient nominations are received to fill all vacancies on the committee, the candidates nominated shall be deemed to be elected and further nominations may be received at the annual general meeting.
- (d) if the number of nominations received is equal to the number of vacancies to be filled, the persons nominated shall be deemed to be elected.
- (e) if the number of nominations exceeds the number of vacancies to be filled, a ballot must be held.

If you have any questions please email Jon Rolfe, the Secretary at secretary@hlttv.org.au, call on 03 9531 2234 or write to Secretary, HLTTV, PO BOX 25036, Melbourne VIC 3004.

Editor's Spring message

Maurice Reid and his wife Denise experienced first hand the challenge of living regionally, yet needing to spend months (and months!) in Melbourne after transplant.

His story is an excellent reminder of why our subsidised accommodation program is so important.

We've also seen some real growth in progress for our next major fundraising adventure - The Tour de Transplant, an incredible cycling adventure, covered in previous pages. And lastly, we remind all members

of the AGM to be held next month - see below for the notice, and proxy forms.

Wishing you good health, The Circulator team

Spring edition editor - Belinda MacLeod-Smith, with plenty of support and contributions from Camille Condon and Claire Stubber.

Contact us on circulator@hlttv.org.au)



Notice of Annual General Meeting and proxy form



**Annual General Meeting of the Heart and Lung Transplant Trust (Victoria) Inc.
to be held 7.30pm 12 November 2013 at**

5th Floor Seminar Room ,The Alfred Hospital, Melbourne

Proxy for voting at the annual general meeting

Under Rule 19 of the Constitution of the Heart and Lung Transplant Trust (Victoria) Inc.:

- “(1) each member is entitled to appoint another member as a proxy by notice given to the Secretary no later than 24 hours before the time of the meeting, or handed to the Secretary by the time of the meeting, in respect of which the proxy is appointed; and
- (2) the notice appointing the proxy must be—
- (a) for a meeting of the Association convened under Rule 7(7), in the form set out in Appendix 2; or
 - (b) in any other case, in the form set out in Appendix 3.”

Appendix 3 requires the following form of appointment of proxy:

“I, (*name*), of (*address*) being a member of the Heart and Lung Transplant Trust (Victoria) Inc. appoint (*name of proxy holder*) of (*address of proxy holder*) being a member of that Incorporated Association, as my proxy to vote on my behalf at the *annual/*special general meeting of the Association to be held on—(*date of meeting*) and at any adjournment of that meeting. My proxy is authorised to vote *in favour of/*against the following resolution: [*insert details of resolution*]

Signed, Date”

This proxy form is to be used for appointing a proxy at the Annual General Meeting to be held on 12 November 2013 at 7.30pm 5th Floor Seminar Room, The Alfred Hospital Melbourne. The purpose of the meeting is to receive and consider the general business of the annual general meeting.

Transplant anniversaries - we wish you many more

July

Lung/s

- Rachael Bradley, 2009
- Allan Browne, 2002
- Tricia Martakis, 2011
- Geoffrey Puddy, 2004
- Kathryn Wright, 2010
- Steve Wright, 2011

Heart

- Vern Cox, 1995
- Russell Freeman, 2005
- Denis Glascott, 1999
- Eric Holt, 2011
- Bev Hume 2010
- Claude Turco, 2007

Heart and Lungs

- Brian Guy, 2008

August

Lung/s

- Nicci Le Lant, 2012
- Catherine Liddell, 1997
- John Mills, 2008
- Robert Picken, 2012
- Sivaraman Sivapiragasam, 2011

Heart

- Ian Ashby, 1997
- Wes Evans, 2012
- Neville Eyre, 2002
- Ken Fulton, 1997
- Steve Rowell, 2008
- Demir Terziu, 2008
- Dean Thompson, 2009
- Robert Webber, 1998
- Stephen Kinson 2012

September

Lung/s

- Shirley Aisbett, 2008
- Martina Appelman, 2009
- Ann Bumpsted, 2012
- Ian Francis, 2010
- Ronald Graham, 2010
- Hassell Rutland, 2009
- Louisa Walsh, 2010

Heart

- Lloyd Honeycombe, 2000
- Monty Kleiman, 1993
- John McLean, 1991
- Sammi Tabone, 2009



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: Secretary Heart & Lung Transplant Trust (Victoria) Inc
PO Box 25036, Melbourne, Vic, 3004

Please visit <http://www.hlttv.org.au/> and follow the 'Membership' link to pay online.

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.

An membership reminder will be included with the June 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.

For enquiries email membership@hlttv.org.au



Heart & Lung Transplant Trust (Victoria) Inc

Bringing The Alfred transplant family together.



Sunday November 24th 2013
11.30AM at Fawkner Park
(opposite Alfred Hospital)

The Christmas BBQ is a great social event for pre and post transplant patients, families, carers and friends. BBQ and drinks are provided (including vegetarian options). Please BYO salad.

Great raffle prizes on offer - donations for Christmas Hampers and raffles are most welcome and can be left at 5th Floor Reception

Contact: Jeff on 0425 782830 or email: events@hlttv.org.au

BYO tables and chairs and don't forget the sunscreen!