



# the Circulator

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

Fourth Quarter | 2013 | Issue No. 75

## Tour de Transplant is Go



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# President's Message

As this is the last Circulator for 2013 it provides the opportunity to reflect on the past year at HLT TV. Membership of our organisation has increased in numbers and our Facebook friends and Twitter followers have also grown in numbers.

In October we were able to increase the number of apartments at Park Regis, Griffin Suites from 2 apartments to 3 available for our country and interstate heart or lung transplant recipients and their carers. This scheme known as the Second Chance Accommodation Program provides accommodation at a notional \$15 per day for those undergoing the 3 months of post-operative outpatient medical rehabilitation and monitoring who are unable to return home. As you know by now, this important program relieves much of the financial pressure for our country and interstate recipients and their families.

Your Management Committee has been very busy raising funds to support the Second Chance Accommodation Program financially. We are now engaged on the biggest fund raising effort in the history of HLT TV. The committee has appointed Jon Rolfe, our past secretary and treasurer, as chair of the Second Chance Task Force committee. Whilst we shall greatly miss Jon's immense input on the Management Committee, he is critical to the fund raising initiatives and so is of much more value in that role.

The Tour de Transplant, planned for next March, has now an almost full complement of participants including 3 of our members who have each had transplants along with nurse Kelina Attard from the lung transplant unit. We have se-

cured sponsorship from KPMG, the Staywell Hospitality Group (the parent company of Park Regis), Campitelli Consultancy and 3AW has joined as our radio supporter. Negotiations continue with other potential corporate sponsors.

Earlier in the year I wrote a letter that I sent to each member asking you to consider a small local fund raising effort in your community. The response has been wonderful with so many of our members raising money in so many inventive ways. This help from you has enabled us to add the third apartment at Park Regis. I sincerely thank all of you who have gone to the trouble of organising your local event. It has already made a truly great difference.

I am delighted to announce that we have signed a partnership agreement with Staywell in which they have agreed to raise funds in a variety of ways for HLT TV and the Second Chance Accommodation Program. This is a very important initiative for both Staywell and HLT TV.

At the Annual General Meeting a new committee was elected and we welcome Rebecca Berry who is taking on the important role of secretary and Vanessa Scott who has indicated that she is willing to become our new Membership Officer. Louisa Walsh is retiring as Membership officer but will stay on as Vice-President of HLT TV. Claire Stubber, Belinda Macleod-Smith and Camille Condon who between them edit and produce The Circulator were also formally elected to the committee. I am pleased to say that we have an active and engaged committee at

work. It is important to note that we employ no paid staff and all work is done on a volunteer basis. This is vital message to get across to potential donors and supporters of HLT TV when you approach and speak to them as many of you do.

Our annual Christmas BBQ was held on the last Sunday of November at Fawkner Park opposite The Alfred, as usual, with about 150 members and their families in attendance. Everyone seemed to enjoy catching up with old friends and we held our traditional successful raffle organised and run by Martina Appelman. Our Events Coordinator, Jeff Campbell, once again organised the event brilliantly and John Prior along with family and friends cooked the food perfectly. Thanks to all involved!

As we approach Christmas and the festive season I want to wish you all a very Merry Christmas and a Happy and Healthy New Year. Those of you who are enjoying your second chance enjoy every moment and those who are on the waiting list I hope that "the call" comes very soon.

David Hayne

President of the Heart and Lung Transplant Trust (Victoria)

[president@hlttv.org.au](mailto:president@hlttv.org.au)



# A note from the editor

The Heart Lung Transplant Trust (Victoria) is a busy entity to be a part of at the moment. The much anticipated Tour de Transplant has one rider registration to go before the full quota is reached due to a fantastic effort on the part of former HLTTV secretary, now Second Chance Task Force Chairman, Jon Rolfe, retiring KPMG Partner, Gerry Hanily and Campitelli Consultancy Director, Greg Campitelli. In this edition you will see reports on some of the events that were held to encourage these riders to register. The annual end-of-year/Christmas BBQ was held and had a large attendance, reasonable weather and the provision of a good social occasion. The HLTTV Annual General Meeting was held on the 12th of November and we are pleased to welcome Louisa Walsh as our new Vice-President and Rebecca Berry as our new Secretary. We thank profusely for their efforts former Secretary Jon Rolfe and former Vice President Rom Konieczny, and take the opportunity to thank Jane Cooper our current treasurer whom we are looking to replace (see ad on page 10) who has done a marvellous job despite the tyranny of distance. We wish all our readers the best of health and much happiness for the festive season.

**Editor for Quarter 4: Claire Stubber**

**Camille Condon**

**Belinda Macleod-Smith**

[circulator@hlttv.org.au](mailto:circulator@hlttv.org.au)

## Welcome to Our New Members for 2013

Ann Bumpstead  
Paul Gloede  
Stephen Kinson  
Nicci Le Lane  
Katrina McKenzie  
Robert Picken  
Helen Rankin  
Andre Wilmann  
Elizabeth Johnson  
Matt Adams  
Dale Constable  
Dinah Newhouse  
Marian Summer  
Vicki Yfantis-Cocossis  
Julie Hunter  
Elzbieta Slizankiewicz  
Carole Bloomer  
Rebecca Berry  
Colleen Berry

### HLTTV contacts

**President** | David Hayne

Ph: 041 814 8919

[president@hlttv.org.au](mailto:president@hlttv.org.au)

**Vice president** | Louisa Walsh

Ph: 041 851 4227

[vicepresident@hlttv.org.au](mailto:vicepresident@hlttv.org.au)

**Secretary** | Rebecca Berry

Ph: 045 888 5916

[secretary@hlttv.org.au](mailto:secretary@hlttv.org.au)

**Membership officer** | Louisa Walsh

Ph: 042 750 9042

[membershipofficer@hlttv.org.au](mailto:membershipofficer@hlttv.org.au)

**Patient support** | John Bisiach

Ph: 042 745 5482

[patientsupport@hlttv.org.au](mailto:patientsupport@hlttv.org.au)

**HLTTV events** | Jeff Campbell

Ph: 040 003 1698

[events@hlttv.org.au](mailto:events@hlttv.org.au)

Cover and event photos: Ian Stubber

[snaphappyian.zenfolio.com.au](http://snaphappyian.zenfolio.com.au)

## 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 two, 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

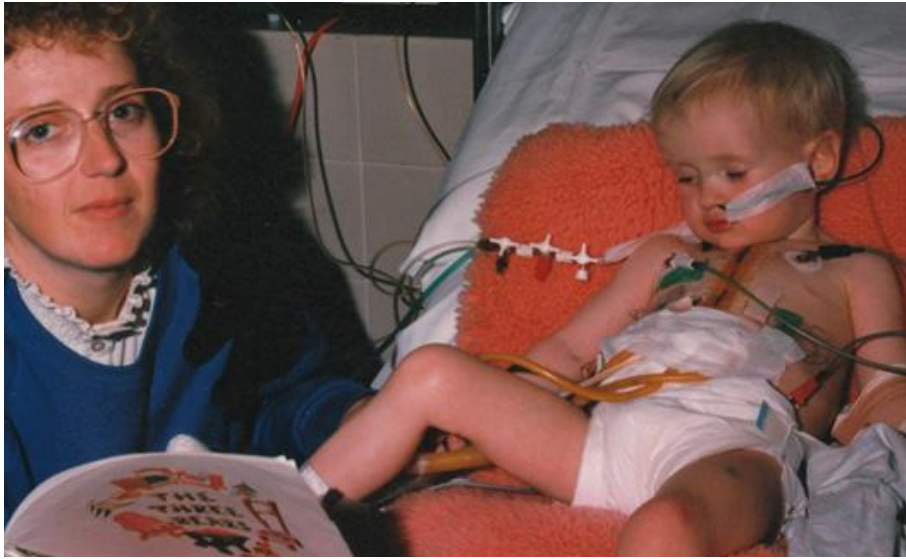
**Email** | [griffin@parkregishotels.com](mailto:griffin@parkregishotels.com)

**Web** | [www.parkregisgriffinsuites.com.au](http://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.



# Matthew Orchard



## Illness progression

I had a fairly normal childhood, I wasn't too limited, I remember running around and playing like everyone else. The only thing that made me know I was different was the big scar on my chest, my parents being a little more protective than normal, monthly trips into the Royal Children's Hospital (RCH) for warfarin monitoring and of course the cardiology appointments often involving long waits and confused sonographers. As I got older I noticed that the gap in physical ability really began to grow. While I still tried to be involved in sport in high school I focused on playing positions such as goalie or catcher where I wouldn't have to run as much as others. When I was 16 I got my first job at Safeway and quickly found myself in the seafood department gutting fish, which was definitely something different to what all my friends were doing. On Christmas Eve 2002 I had a 12 hour shift on what was the busiest day of the year selling a week's worth of stock in one day. It was when I got home that I realised that I wasn't just tired, something was wrong, I could feel it in my chest, a tight throbbing.

It was about eight pm on Christmas Eve and I had to tell my Mum that I thought that something was wrong. It was only a few minutes until we decided we had better go into emergency, as all my medical records were at the RCH, naturally we thought that it was best to go there. Approaching triage, being seventeen and telling them that I was expecting to be seen by them they weren't particularly happy to see me and suggested I would be better off going to an adult hos-

*Matthew, age two, and his Mum Rosette after his first open heart surgery*

*At the time of writing this it is exactly two years that I have been on the waiting list for a heart transplant. Not that I'm counting; seven-hundred and thirty days or sixty-two million seventy-two thousand seconds... As I'm sure many of you know, those years have been filled with a mixture of emotions, leading the charge would have to be anxiety and stress. My story however doesn't really start anywhere near two years ago.*

I was born with a complicated cocktail of heart defects with lots of abbreviations, primarily; SV, HPRV, VSD, PA, AR or Single Ventricle, Hypoplastic Right Ventricle, Ventricular Septal Defect, Pulmonary Atresia and Aortic Regurgitation. I have what's colloquially known as 'half a heart' and to make everything more complicated I have Situs Inversus which means all my internal organs including my heart are on the wrong side.

## Initial Surgery

I'm lucky in the sense that I hav

en't had to have too many surgeries. My mother tells me that shortly after I was born she started to raise questions with doctors and nurses concerned as to whether I was ok. As I turned from healthy pink to purplish-blue, the hospital staff began to listen and realised that I needed immediate surgical intervention. It was then that my parents met for the first time Dr T.H. Goh whom I saw for over two decades. At thirty-six hours old I had my first surgery, a Blalock-Taussig shunt. This shunt is a redirection of blood flow which was a stop-gap to help me survive until I was old enough to survive a more permanent surgery.

At two I had a Fontan Procedure(- for a diagram see <http://www.fontanregistry.com/the-different-forms-of-fontan-procedure.aspx>), over the years the Fontan Procedure has changed in a number of ways. Back in 1987 when I had my first Fontan the right atrium was directly connected to the pulmonary artery; this would prove later to be a massive problem.



pital. By that stage I felt so unwell I could barely stand, reluctantly they gave me a once over and realised that I didn't look too well and I was taken in and put on a monitor.

Apparently sometimes atrial flutter and atrial fibrillation can be difficult to detect. This proved to be a barrier as after I had been examined by a few doctors and registrars they thought that it would be a good idea to offer me something for indigestion. Frustrated I agreed to take it. As I laid there I thought to myself "how can I get them to see on the monitor that it is something to do with my heart?" so I thought I would exert myself a little, I sat up quickly and was pleased to see that the heart monitor went crazy. I called them over and told them to watch. Suddenly they realised that maybe it wasn't indigestion and it was an arrhythmia like I had been saying all along. I spent Christmas day in hospital and was scheduled that day to have a cardioversion.

The following year, 2003 my final year of high school I was walking on eggshells. My cardiologist suggested that I may need some kind of surgical intervention and wanted to do a catheter study but had agreed to hold off until I finished high school.

Throughout the year I felt episodes of arrhythmia, though usually it would only be a beat or two or last for only a few seconds. The year went by quickly and was full of excitement, many of my friends and I turned eighteen and began driving to school and enjoying a much freer social life.

The final day of year twelve was again full of excitement, school was over and my friends and I spent the day celebrating like all kids at that time in their lives. Later that evening however the excitement perhaps got the better

of me and sent me into another serious episode of arrhythmia. It was about midnight before I realised that something was seriously wrong, I woke my mother and we made the trip again into the RCH.

This time they were more willing to believe that I was in an episode of arrhythmia and tachycardia.

As before my heart was racing at over one hundred and forty bpm. The doctors decided that they would act quickly and in the early hours of the next morning they performed a cardioversion on me whereby my heart was 'shocked' back into a normal rhythm.

The next thing I remember is waking up in a haze, in ICU, in immense pain. They had shocked me six times unsuccessfully. The positive aspect is that this now makes for a good story, I had been given a drug used to dull the memory of traumatic events so while I was in ICU and drifting in and out of consciousness I kept looking up to my Mum and asking "Will I be able to make it to my formal" to

which she replied "Probably not." This answer upset me and I fell asleep, only to wake up moments later and ask the same question. Mum having a difficult time breaking the news to me over and over decided to change her answer to "we will talk about it later".

I ended up making it to my year twelve formal four days later although I was still in the arrhythmia so I was given the warning that if I didn't make it back to the hospital by midnight my heart would turn into a pumpkin. It took me about three months to recover and I ended up missing all of my exams. Fortunately I was able to get some special consideration and received my VCE.

### What now?

The eighteen months following this event were filled with just about everyone wondering "what now?" I was put on Amiodarone and a number of other drugs to try to control what had progressed into very frequent episodes of



*Matthew writes: This picture is only a few days after surgery, the nurses were hounding me to keep my head up so I devised the plan to hold my head up with my hand.*

arrhythmia. I was handballed around between a number of specialists and countless procedures were performed.

As I previously mentioned, I had my Fontan in 1987 and the right atria was directly connected to the pulmonary artery, this caused the right atria to have scar tissue on it and it to be enlarged. The right atrium is where the primary pacing cells are located, so this enlargement and scarring is very bad for the longevity of Fontan patients and believed to be the primary cause for most of my arrhythmia issues.

At this time in Australia there was no such thing as a Fontan revision. While my cardiologist was investigating what could be done and who would do it we looked into the possibility of getting treatment overseas.

Luckily in mid-2005 an answer had come. My cardiologist had contacted Mr Andrew Cochrane and he developed a plan to perform a 'Fontan Revision' consisting of; removing most of my damaged right atrium, converting my Classic Fontan to the Extra-cardiac Fontan and installing a pacemaker.

I was the first in Australia to receive a Fontan Revision, since me there have been many other young adults requiring similar surgery. The surgery ended up taking the better part of eleven hours and I was on bypass for close to five. As far as Open Heart Surgery (OHS) goes recovery was fairly normal. It was the first OHS that I was actually old enough to remember, the experience is something I don't wish on anyone and I don't look forward to that part of the transplant process.

It was a full year until I felt as though I was in a better place post-surgery. Although the in-



*Matthew after his Fontan Revision*

stant improvement of not having arrhythmias was a huge bonus.

#### Short lived health

The positive aspects of the surgery were short lived. It wasn't long until it was discovered that I was still in heart failure and my exercise tolerance wasn't anywhere close to where it should be for a man in his early twenties.

At the beginning of 2009 my paediatric cardiologist who had seen me since the day I was born said goodbye and best wishes as he transferred me to the care of Dr Peter Bergin in the Heart Failure clinic at the Alfred.

For the next three years I was in a state of purgatory while the inevitable decision that transplantation was the best option was decided. After years of a slow decline and poor quality of life Peter Bergin gave the order to go ahead with assessment for transplantation.

#### Officially waiting

On October 25 2011 I was officially on the waiting list for a heart transplant.

Being on the waiting list has been hard as I'm sure many of you understand. I have family interstate that I haven't been able to visit and my Mum feels anxious about leaving me so she hasn't travelled

either. I've also missed a best friend's wedding and my grandmother's funeral.

I'm in the final weeks of what has been a long journey to completing a Bachelor of Health Science. I'm excited about the prospect of finishing and hope it will help me be an advocate for promoting organ donation and awareness of congenital heart disease.

I look forward in anticipation for what my life has the potential to become, I hope that a transplant will give me a new lease on life and I'll have the ability to be a strong active young man.

For now though, every time the phone rings, I get anxious, I hope.  
-Matthew Orchard



**GiveNow.com.au**  
Give more, give smarter, give better, give now!

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



# Launching into the Tour de Transplant

On the 24th of October, about 50 participants and supporters attended a magnificent launch for the inaugural Tour de Transplant cycling event. Hosted by major sponsors KPMG in their impressive Collins Street boardroom, attendees were treated to a special presentation from tour leader, Australian cycling legend Phil Anderson and freelance cycling commentator Matt Keenan.

Matt Keenan, a firm supporter of the event and HLTTV, made it clear that his support is “for the long haul” after being inspired by his childhood friend Simon Renn who received a double lung transplant as a result of cystic fibrosis. Readers will no doubt be familiar with Matt from SBS coverage of the Tour de France.

Jon Rolfe, former HLTTV secretary now embracing the challenge of organizing the Tour de Transplant and coordinating the HLTTV’s newly created Second Chance Taskforce, also gave an inspiring presentation about his transplant journey.



*HLTTV President David Hayne*



*Phil Anderson (L) and Matt Keenan (R) answering questions*



*Jon Rolfe and Matt Keenan*

Phil Anderson, our Tour de Transplant leader, spoke enthusiastically about the challenge and the camaraderie that participants will enjoy on our Tour. We were privileged to watch a video of highlights of his illustrious career and to hear of some of his past experiences from the Tour de France.

President David Hayne has been overwhelmed by the support shown by members, supporters and organisations.

“In addition to our major supporters KPMG and the Staywell Hospitality group, we continue to be incredibly grateful and overwhelmed by the support of HLTTV members, and the many offers of help being made,” said David.

“While we are close to the full number of riders, there’s still room for a few more, and as training rides have commenced, I encourage potential riders to visit the dedicated Tour de Transplant website – [www.tourdetransplant.org.au](http://www.tourdetransplant.org.au) and register for the event there. Even if you are not a cyclist then you can still help by donating to the Tour; visit the website and follow the “Donate to the Tour” link

If you’d like to participate or help promote the Tour de Transplant, then please get in contact with Jon on 0432 845662 or email at [jon@hlttv.org.au](mailto:jon@hlttv.org.au).

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**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 Camille and Claire by email | [circulator@hlttv.org.au](mailto:circulator@hlttv.org.au)  
Items for review can be posted | Editorial team C/O PO Box 25036, Melbourne, Vic, 3004.**

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# GoFundraise Demonstration Evening

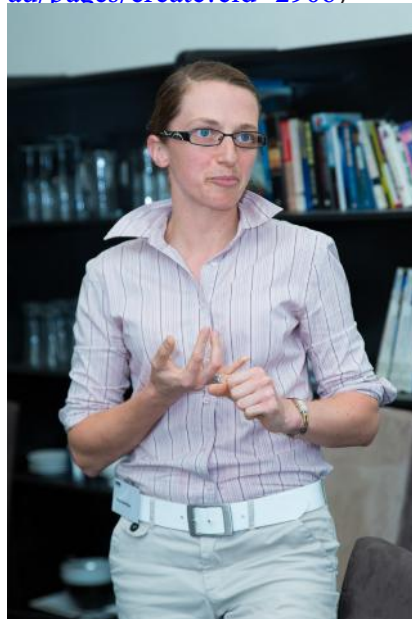
On the evening of the 26th of November we hosted a Tour de Transplant event at the Hawthorn offices of GoFundraise, an internet based company that provides resources for fundraising events and is helping HLLTV with our fundraising efforts for the Tour. The event was designed for our Tour riders to maximise their use of the Tour's website fundraising portal, it was also attended by Second Chance Task Force members and a few interested others. Each rider has their own fundraising website page linked to the Tour, which is hosted by GoFundraise. In fact anyone can set up their own Tour fundraising page to assist our efforts in raising funds for the Second Chance Accommodation Program (visit [www.tourdetransplant.org.au](http://www.tourdetransplant.org.au) for details, or see below).

David Hayne, our President, introduced the event and thanked GoFundraise, and in particular Fiona Macmillan, for allowing us to use their facilities. Jon Rolfe, Chairman of the Second Chance Task Force, updated everyone on the Tour including details of the first group training ride scheduled for 15 December.

Fiona then demonstrated how an individual's page operates, how they can maximise the number of people who see the page by linking their site address automatically to any emails they send and their social media networks (Facebook/Twitter). Martina Appelman, HLLTV's champion fundraiser, gave everyone tips on how and what type of fundraising events can be organised. Greg Campitelli who provides fundraising support to HLLTV also spoke about ways to maximise fundraising opportunities. We

have produced a short document on fundraising tips (10 of which appear opposite) which can be found on the Tour de Transplant website under the menu item Fundraising Tips (or directly here <http://tourdetransplant.gofundraise.com.au/cms/fundraising-tips>).

If you are interested in supporting the Tour de Transplant as a non-rider then you can create your own GoFundraise fundraising page by visiting the Tour's website and clicking on the button Non-Rider Fundraising (or directly here <http://tourdetransplant-nonriders.gofundraise.com.au/pages/create?eid=2906>)



Above: Fiona Macmillan

Below: Riders Kelina Attard clinician nurse on 5 (L) and Rebecca Berry, lung transplant recipient (R)



## HLLTV's Great Fundraising Ideas

HLLTV has developed these great fundraising ideas based on its experience and if you think of a better idea please let us know!

### 1. Host a Dinner

Invite 10 close friends and ask them each to donate a sum eg \$50 or \$75 per head, which equals what they may pay for a really nice night out at a restaurant. Provide a three-course meal and wine – can raise up to \$1,000.

### 2. Trivia / Quiz Night

Book the local school or church hall, invite friends over – set up teams of 5. 10 teams – everyone pays \$20 to come along – can raise \$500 – \$1,000. Make the event a BYO platter. HLLTV already has the quiz / questions / answers.

### 3. Street BBQ

Set up a BBQ in the street – let everyone know it's on and sell sausages @ \$3 and burgers @ \$5 – all for a great cause – can raise over \$400.

### 4. Wine Tasting Night

Invite friends over charge and entry fee to attend. Provide a variety of wines – white & red, provide cheese and biscuits. The wine could be donated by a local bottle shop or local winery. Invite the owner of the business to attend and promote their product on the night. You could have a blind tasting with the winner getting a prize. 25 friends @ \$25 per head = \$500 raised.

### 5. Film Night

Approach local cinema, book out one of the theatres for a set time. The cinema will give a discount for these large bookings. You charge \$30 per person to attend, have finger food and drinks on arrival. You can run a small raffle at the event. These events can raise over \$2,000+.

### 6. Lawn Bowls



Book local club they will usually provide it for free or very low cost if it is a charity event. The club will provide coaches for free to help teach the teams the rules. This is a great family event. 64 people bowling at \$10 a head = \$640 raised.

#### 7. **Community Garage Sale**

Get together with local neighbours and put on a combined street garage sale. This will attract many more visitors than usual. Explain to customers that all money raised is going to charity – which means they will be willing to pay a bit more than usual.

#### 8. **Card Night**

Invite the lads or ladies over for a card night. Set entrance fee and use betting chips. Winner of the night gets a prize eg dinner for two at a local restaurant, which has been donated. 8 people over at \$50 = \$400 raised.

#### 9. **Fashion Night**

Approach local fashion outlet and ask them to host a fashion night. Invite all your friends with a set entrance fee, which goes to HLT-TV.

The fashion outlet potentially makes money on any sales. The store will often donate an item that can be auctioned for charity. Provide champagne and nibbles on arrival. 20 friends at \$50 = \$1,000.

#### 10. **Art Night**

Approach your local school or kinder. The children with help from the art teacher paint a family portrait on canvas. Then host an Art Show where the works are displayed. Provide drinks and nibbles. Place red dots on sold items. All items are one set price of \$25 per artwork.

Every family will buy their kid's work. This can easily raise over \$1,000+.

[www.hlttv.org.au](http://www.hlttv.org.au) [www.tourde-transplant.org.au](http://www.tourde-transplant.org.au)

## **This fundraising effort takes the cake**

Every cent raised by the Heart and Lung Transplant Trust is important, and often the stories behind particular fundraising efforts really touch our hearts. This quarter a very special contribution was received from Kailah Mitchell of Ballarat.

Kailah (27) is granddaughter to Graham and Maggie Mitchell. A very close family, Kailah has been a big part of her grandparent's lives, and particularly her grandfather's transplant journey.

Graham Mitchell received his gift of life in the form of a double lung transplant at the Alfred Hospital on Boxing Day 2011. As a result, Kailah is a big fan of anything that will help the organisations that

support transplant recipients. So when Kailah saw HLTTV President David Hayne's March letter encouraging members to fundraise, she couldn't help having a chat to her supervisor and workmates at Ballarat Regional Industries (BRI) about what they could do.

BRI is not-for-profit organisation providing employment opportunities for people with disabilities, and with the support of her supervisor (who organised signs and promotion) Kailah baked, decorated and sold more than 80 cupcakes to her workmates and friends, and this, alongside other fund raising efforts raised \$450 for the HLTTV.

President David Hayne is incredibly grateful and impressed by Kailah's effort.

“Kailah has truly shown her beautiful and generous spirit with this fundraising activity – we thank her, and all our members, their families and friends who have contributed this and every year.” There are many ways to ensure HLTTV can continue funding our support for transplant recipients - fundraising ideas can be found on the 'fundraising' tab of the HLT-



*Thank you to Graham Mitchell (R) and his granddaughter Kailah*

### **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



# Do. Good Stitches Quilt Hand Over

It was a pleasure to meet the recipient of the do good stitches quilt,



Denice Hansen (above with quilt). In her note to the anonymous quilters, written after her recent transplant, it is evident that she was touched by their kind gesture, she writes:

‘What a wonderful gift to receive – not so long after my transplant gift and another chance at life.

*What a wonderful gift to receive - not so long after my transplant gift and another chance at life. The quilt has given not only me great pleasure, there has been so many people comment on it and how lovely it is. Such a variety of people I have felt great warmth and comfort from it and not just in a physical sense. It has brightened my stay in hospital and I enjoy exploring each panel. Thank you to the quilters Denice Hansen*

The quilt has given not only me great pleasure, there has been so many people comment on it and how lovely it

is. Such a variety of people. I have felt great warmth and comfort from it and not just in a physical sense. It has brightened my stay in hospital and I enjoy exploring each panel.

Thank you to the quilters Denice Hansen’

The quilting group have now generously donated a second geometrically themed quilt which was handed to Lung Transplant Clinic nurses Rani Martin and Kelina Attard last month.

Top: Rani Martin and Kelina Attard hold up the new do. good stitches quilt and Above: the geometric design of the front side of the new quilt

## Treasurer Wanted

The committee of the Heart Lung Transplant Trust (Victoria) is looking for a treasurer to replace the outgoing Jane Cooper.

This is a voluntary position. We require someone with book keeping, accounting or financial experience. For more information and to apply for this position please contact HLTTV President David Hayne:

ph: 0418148919

email: [president@hlttv.org.au](mailto:president@hlttv.org.au)

Address:  
President  
Heart and Lung Transplant Trust (Victoria) Inc  
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.



## Thank you Janet Johnson and the Communities that Helped her Fund Raise

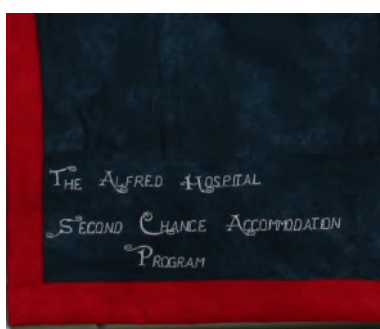
Recently HLTTV President David Hayne was delighted to receive a letter - the contents of which appear below - and a generous donation as a result of some wonderful small acts of kindness which add up to a large \$3041.00 contribution to the Second Chance Accommodation Program. Thank you Janet Johnson

My name is Janet Johnson and I am from Robinvale, a small country town, 80km from Mildura on the Victorian/NSW border who received a life saving double lung transplant on 4th October 2011. I believe everyone has a story to tell and this is mine. When my son was seventeen, after hearing of organ donation he said he wanted to be a kidney donor, I looked at him and said that wouldn't be a decision I would have to make! Little did we know when he was 20, sitting at the Mildura hospital with my sister after a car accident we had to do exactly that. The doctor said "He is such a strong, healthy looking young man" - I didn't realize what he was asking until my sister said "Jan he is asking permission for organ donation." So of course knowing his wishes, they were upheld. Never thinking that one day I would be relying

on the generosity of an unknown family for my second chance, to whom I am forever grateful. After transplant my 2 grandchildren said to their mother, "How will we find Ma Ma now if she isn't in the family room? She doesn't have an oxygen lead to follow". When the Alfred wrote requesting

it decorated, another sister gave \$100, a business house offered to hold a sausage sizzle in front of his shop and even supplied sausages, bread etc, all we had to do was provide the cooks! My son-in-law Rod, did an excellent job. Daughter, Donna and grandchildren Jock 14 and Kenna 12 were his helpers, while I sold raffle tickets. As my husband Noel, is a bowler we decided to hold a special bowls day, also starting with a sausage sizzle cooked by Noel and good friend Digger. Euston Post Office and Take Away owned by the Mannix family donated \$200 in prize money for the day and Nooy's hot bread shop donated banana cakes and date slice for afternoon tea. My three sisters came from Mildura to support me and good friends made tea and coffee and collected cups and empty stubbies all day.

Friends from Essendon (where Noel bowled for the 3 months we were in Melbourne and kept him sane!) and Ballarat offered to place collection containers on the bar of their local clubs. (continued on page 12)



members consider a fund raising activity for The Second Chance Accommodation Program, my goal was to raise \$1,000. I had been working on a quilt so decided I would get it finished and raffle it for the program, one of my sisters made a Christmas cake and had

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So I approached several business houses and left containers on counters in Robinvale.

Generous people gave cash donations which raised \$505.

So I am delighted to be able to contribute \$3,041.00 to HLLTV for the "Second Chance Accommodation Program" and at the same time publicly thank the team responsible for all the care given to me over many years. Glenn Westall and Lynda Holdsworth for all the trials we participated in prior to transplant. Professor Greg Snell and his team on the 5th floor for their continued support. Also the transplant clinic nurses who say nothing is too much trouble, I sincerely thank you all.

Last, but by no means least my precious husband who has been through some tough times with me.

## Coco-Nutty Granola

*The rice malt syrup in this recipe is optional – I personally don't sweeten my granola at all. Perhaps make half a batch with the syrup, half without and see what you like. I like to eat this granola with yoghurt – nice and chunky.*



## Coco-Nutty Granola

This is what you need:

3 cups coconut flakes  
2 cups almonds, cashews, pecans, walnuts, pepitas, roughly chopped (you can use either one type or a mixture)

2 tablespoons chia seeds

1 teaspoon ground cinnamon\* (optional)

80–100 g coconut oil or butter, melted

3 tablespoons rice malt syrup (optional)

Preheat the oven to 120°C\* and line a baking tray with baking paper. Combine all the ingredients, then spread evenly on the tray. Bake for 15–20 minutes until golden, turning halfway through the cooking time. I like to bake mine until quite dark – the darker it is, the crunchier it is. Remove from the oven and allow to cool, then eat while it's still crispy.

Variation: If you wish to add rolled oats, toss 2 cups into the bowl with the rest of the ingredients, and add a little more oil and syrup.

*This recipe is reprinted with kind permission from Sarah Wilson's "I Quit Sugar", for this and other sugar free recipes visit:*

[www.iquitsugar.com](http://www.iquitsugar.com)

*Photograph: Marija Ivkovic*

\* I use 1 tablespoon of cinnamon and I have the oven on 180C and turn the Granola after 10 minutes - ed

Jacqui Anderson, Senior lung transplant clinic dietitian, advises that granola is high in calories so for those watching their weight and cholesterol, keep serve sizes small perhaps 1/3 cup at most.

## Camille's Great Strides



I

In late October, I took part in my second charity walk since my double lung transplant earlier this year. Even though I don't have CF, I've made some wonderful friends via the HLLTV that do, and I really wanted to do something to support them. The Cystic Fibrosis Victoria Great Strides Walk was the perfect opportunity.

I attended Pulmonary Rehabilitation every week for around nine years prior to my transplant, and so I asked the two lovely Western Health Physiotherapists who ran my program to join me. I was also joined by my Sister-In-Law. It was a great opportunity for the physiotherapists to see just what an amazing difference a transplant makes after such a short period of time. In their day to day program, they only usually see patients who are pre-transplant.

I managed to walk the 4km course in under an hour (and it included a rather large hill), so I was really happy with that. I also made it into the top ten individual fundraisers for the event which was amazing. There was a huge amount of support from family and friends which was wonderful.

It was so much fun this year, that I can't wait to do it again next year!



# First Training Ride for the Tour de Transplant



*Martina Appelman with some of our star riders: Michael Johnston (L), Kelina Attard and Derek Claridge*



*Tour de Transplant Riding group in action - Phil Anderson leading*



*Left to Right: Andrew of Jerry's Cafe, Phil Anderson and Second Chance Task Force Chairman Jon Rolfe*

Bright and early on the morning of Sunday the 15th of December 19 riders gathered in a car park at St Kilda Marina. This was the riders' first chance to assess their skills relative to their fellow riders and to train for the inaugural 2014 Tour de Transplant. After some quick group photos and advice from Phil Anderson and his partner Annie Newall the riders set off for a 21 kilometre ride. With light winds and a partially cloudy sky conditions could not have been better and the

riders seemed well prepared and competent with most keeping up with Phil Anderson. Annie Newall was on hand to guide and advise those who were not yet ready for keeping up with the peloton. When the riders reached Peter Scullin Reserve in Mordialloc they turned around and rode back along Beach Road to St Kilda. The training ride ended with a social morning tea at Jerry's Cafe in Barkly Street, Elwood. The rid-

ers were provided with delicious muffins, fruit and vegemite toast and coffee and tea. The training ride fostered a great sense of camaraderie among the riders and they now have both the Tour de Transplant and a second training ride to look forward to.

# Transplant anniversaries - we wish you many more

## October

### Heart:

- John Campbell, 2008
- Phillip Felmann, 2005
- Robin Oliver, 2000
- Jeffery Priest, 2008
- John Russo, 1992
- Peter Triffet, 2003
- Libero Viola, 1992

### Lung/s

- Bill Carkett, 2002
- Trevor Davidson, 2009
- Kate Hayne, 2006
- Janet Johnson, 2011
- Valerie Ann Shentze, 2011

### Heart and Lungs:

- Claire Stubber, 1996

## November

### Heart:

- Paul Allen, 2011
- Jennifer Ball, 2009
- Fulvio Filipponi, 1993
- Bernice Hallam, 1996
- Adrian Sayers, 2007
- John Turley, 2002

### Lung/s:

- David Biram, 2010
- Phillip Buckland, 2009
- Ian Casey, 2008
- Lynette Coromandel, 2011
- Paul Gloede, 2012
- Len Hain, 2002
- Carol Ann Hoare, 2009
- Jill Keyte, 2011
- Andrew Kirby, 2009
- Nikola Radocaj, 2002

## December

### Heart:

- David Ash, 2008
- Ena Clark, 1999
- Greg Dartnell, 2004
- Eric Gill, 2009
- David Hales, 1998
- John Jones, 1989
- Dennis McCarthy, 2008
- Helen Rankin, 2011
- Russell Wills, 1991

### Lung/s

- Kenneth Catlow, 1997
- Wendy Jenkins, 2006
- Anne McCarthur, 2011

## 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 renew my membership of the Trust

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](mailto:membership@hlttv.org.au)

# Annual End of Year/Christmas Barbeque

Merry Christmas and Happy New Year to all our HLTTV members and their family and friends

