



## HLTTV RAFFLE RAISES \$3,200 *Details on page 6*



*'Country Life' Quilt donated by the Howlong Patchwork Group*

### FOR YOUR DIARY



#### CHRISTMAS GET-TOGETHER

Sunday 25 November 2012

Details will be provided by email and on the website. You can also contact a Committee Member for details closer to the date (or tel 03 9458 2603).

### MEET FOR LUNCH

12 noon  
Sunday 14 October 2012  
Matthew Flinders Hotel  
667 Warrigal Road, Chadstone  
tel (03) 9568 8004

RSVP by 8/10/12  
Martina Appelman  
tel 9769 5210  
mobile 0409 957 492  
email [martina27@live.com.au](mailto:martina27@live.com.au)

### NOTICE OF ANNUAL GENERAL MEETING

7.30 pm  
Tuesday 13 November 2012  
5th Floor Seminar Room  
The Alfred

All Welcome  
All positions are declared vacant at the AGM

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

### Reminder from the Membership Officer

**Subscription renewals** are now overdue. Please complete the membership form on page 15 and return as soon as possible or renew online at [hlttv.org.au](http://hlttv.org.au)

**(see page 14 for further details)**

## Committee Contacts

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#### **Gaylynn Pinniger**

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## Committee Meeting

9 October 2012 at 7:30 pm  
5th Floor Seminar Room  
The Alfred

Invitation to meet informally at  
Alf's Café prior to the meeting.

## All welcome

*A smile is a curve  
which can set  
things straight*

## President's Message

**I think Victorian** members would agree with me that it has been the coldest winter for a long time. I wonder whether our members in southern states feel the same.

It's great to hear that some of our members are enjoying their second chance. To those who have taken the opportunity to travel either within Australia or overseas, whether for pleasure or to catch up with family, we look forward to your stories.

To those of you who are currently on the waiting list we are thinking of you.

To members who are not well, we wish you a speedy recovery. We hear that some of you have been back into hospital. Our thoughts are with both you and your families.

Best wishes to all of our members who are travelling to the Australian Transplant Games in Newcastle NSW, whether you are competing or supporting, we hope you have an enjoyable time. We look forward to sharing your stories, pictures and experiences with us on your return.

The AGM is fast approaching and I would like to personally invite and encourage you to come along.

There are many exciting projects in progress at the Heart and Lung Transplant Trust. The new Accommodation Program is up and running and for it to be a success we need to do some serious fundraising. We look forward to your ideas, support and more importantly your help.

I would like to take this opportunity to personally thank those of you

who have generously given up your time throughout the year to make the Trust what it is today, and what it will be in the future.

Lastly, if you haven't renewed your membership please do so - we value your support and membership - be a member of 'The Transplant Family'.

**Claude Turco**

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## WELCOME TO NEW MEMBERS

Jill Carter (Supporter)  
Cheryl Long (Carer)  
Matthew (Pre Heart) and  
Rosette (Carer)  
Orchard Henry Smeets  
(Heart 1996)  
Yvonne Tapscot (Pre)  
Steve Wright (Lung/s 2011)

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## Museum of Australia Eureka Prize

[www.eureka.australianmuseum.net.au](http://www.eureka.australianmuseum.net.au)

**Congratulations** to Prof David Kaye who was recently awarded the 2012 NSW Health Jamie Callachor Eureka Prize for Medical Research Translation.

Professor David Kaye, Head of the Heart Failure Research Group at the Baker IDI Heart and Diabetes Institute, has created and translated into clinical use a catheter-based system to control the level of medication at specific sites in the body.

## From the Editor

**Many of us** keep in touch socially with people we have met along our transplant journey. Over a chat in the waiting room, a coffee at Alf's, catching up at a restaurant and even at dinner parties we share our stories. We may take lots of photographs but renowned Australian film maker and liver transplant recipient Paul Cox has gone further and made a film called The Dinner Party (see page 13).

Recently I invited local transplant friends Diana Almonte (who I originally got to know through the Cardiomyopathy Association) and Kathryn Wright (who I only met at the recent Accommodation Program launch) to join me for morning tea. Kathryn was wearing her Miraculous medal (St Catherine du Bac) which she said had been given by a Church volunteer while at the Austin Hospital. She was told to wear it around her neck and say a prayer. She said she received her transplant at The Alfred three weeks later. A lovely story from Kathryn is on page 7.

I have to confess that I was the one who suggested going to a nearby cafe called 'Jam and Cream' - just a little treat! Yes, we did feel guilty - but it was a cold and wet day! Perhaps next time we'll stick to the apples and oranges!

Thanks to Paul Allen (heart transplant) and his carer fiancé Karen Lowe for sharing their transplant journey story (page 8). There also seems to be a theme about feeling guilty when straying off diets (page 12)!

Perhaps an up and coming radio announcer? Pre transplant member



**Diana, Kathryn & Gaylynn**



Coen Ashton seemed a natural when interviewed on 3AW's Father's Day Appeal broadcast from The Alfred. Well done Coen.

The deadline for the next edition is 1 December 2012. Contributions most welcome.

**Gaylynn Pinniger**

### ***A few reasons why it's great to be a dog***

- *Having a wet nose is considered a sign of good health.*
- *If you gain weight, it's someone else's fault.*
- *Personal hygiene is a blast. No-one expects you take a bath every day and you don't even have to comb your own hair.*

## TRANSPLANT ANNIVERSARIES WE WISH YOU MANY MORE

In June Vanessa Scott celebrated the anniversary of her double lung transplant in 1999. Unfortunately we missed including this in the last edition. Best wishes to Vanessa.

Congratulations to those who are celebrating their 10th Anniversaries - Allan Browne and Neville Eyre

### July

**Heart** - Vern Cox (1995), Willi Deyssing (2007), Russell Freeman (2005), Denis Glascott (1999), Bev Hume (2010), Claude Turco (2007), Eric Holt (2011), Agapi Nicolaou (2009)

**Lung/s** - Rachael Bradley (2009), Allan Browne (2002), Geoffrey Puddy (2004), Tricia Martakis (2011), Kathryn Wright (2010), Steve Wright (2011)

**Heart/Lung** - Brian Guy (2008)

### August

**Heart** - Ian Ashby (1997), Neville Eyre (2002), Ken Fulton (1997), Robert Mason (1997), Greg Moloney (2006), Demir Terziu (2008), Dean Thompson (2009), Robert Webber (1998), Darren Moyle (2010), Steve Rowell (2008)

**Lung/s** - Catherine Liddell (1997), John Mills (2008), Sivaraman Sivapiragasam (2011)

### September

**Heart** - Paul Heeney (1996), Lloyd Honeycombe (2000), Monty Kleiman (1993), John McLean (1991), Sam Tabone (2009)

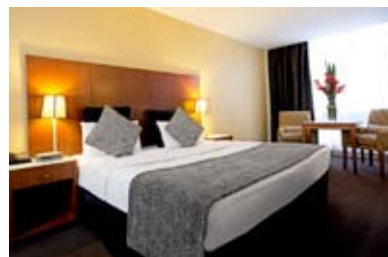
**Lung/s** - Shirley Aisbett (2008), Martina Appelman (2009), Ian Francis (2009), Ronald Graham (2010), Louisa Walsh (2010), John Yeats (2009), Hassell Rutland (2009)

## Park Regis Griffin Suites

Situated between Melbourne's city centre and popular St Kilda Beach. Features include spacious and stylish studio, one and two bedroom apartments, onsite café/bar and tram at the door.

Conveniently located on St Kilda Road with a tram stop directly opposite the hotel, Park Regis Griffin Suites is the perfect choice for guests who need to be in easy reach of all that Melbourne and its surrounds have to offer.

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Location: 604 St Kilda Road, Melbourne • Phone: (03) 8530 1800 • Email: [griffin@parkregishotels.com](mailto:griffin@parkregishotels.com)

<http://www.staywellgroup.com/hotels/melbourne/park-regis-griffin-suites>

For those looking for accommodation close to The Alfred, check with the Park Regis for any discount rates that may be available to The Alfred patients and families.

# Staff Profiles

## GEORGIA MINIO

*Heart Transplant Clinic Nurse*



Hello, my name is Georgia Minio and I have recently joined the team in the Heart Transplant Clinic.

I started nursing twelve years ago, here at The Alfred. My first position was in the Cardiology Ward where I first encountered a heart transplant recipient, and I've been hooked ever since. I completed my Graduate year and then moved to the Cardiothoracic Ward so I could explore the world of LVADs and transplantation further. It is in this environment that I have remained ever since and found an area of cardiac nursing that fascinates me and makes me want to expand my expertise. Over the past three years I have undertaken and completed my Post Graduate Diploma in Cardiac Nursing (which I am very proud of, no mean feat with a young family to look after!) and felt it was time to spread my wings and attempt to achieve another long term career goal which is to work in the Heart Transplant Clinic. I look forward to working with and getting to know such an amazing group of people including staff, recipients and carers.

## KATE WESSELINGH

*Endocrine Nurse Specialist  
Department of Endocrinology & Diabetes*

Some of you will know Kate from when she was working as a Nurse in Ward 5E. Taking over from Fiona who had been in the position for 30 years, Kate has been enjoying her new position down the corridor since March. Kate will no doubt get to know a number of us transplantees in this new position.

Did she enjoy her recent skiing holiday at Falls Creek? Would she recommend snowboarding? Well that depends .....



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\$1 from every booking made on this site is donated to the Heart and Lung Transplant Trust

## RAFFLE RAISES \$3,200



Thanks to Rom Konieczny for his effort in organizing the raffle and to Martina for taking over to help out when Rom's employment took him interstate. And thank you to everyone for your fantastic support in buying and selling the raffle tickets.

Martina Appelman, Gaylynn Pinniger and Anne Poole were on hand to sell tickets at The Alfred. 200 tickets were sold on the day - mainly to the 'transplant community'. Thanks also to Anne's husband Neal for his help. A big thank you also to Alf's Cafe for allowing us to set up in the cafe as it was a much warmer spot!

The draw took place as advertised on 29 June 2012 at the 3F Clinic, The Alfred. Social Worker Jane Harris drew out the raffle winners in the presence of HLTTV representatives and a small number of attendees.

## Congratulations to the winners:

### 1st Prize - John Stephenson of Sunshine

Two Nights Accommodation at "Bellevue on the Lakes", Lakes Entrance

\$100 Dinner Voucher at Lakes Sports and Community Club

Trip to Wyanga Park Winery on the ferry "Corque" which includes lunch for two (conditions apply)

3 Hour Fishing Trip for two on the "Mulloway"

### 2nd Prize - Mrs Val Hocking of Ballarat

"Country Life" Patchwork Quilt 1.16 m x 1.16 m - Donated by heart transplant recipient Jill Reid and her Howlong Patchwork Group

### Please support our sponsors:

#### Bellevue on the Lakes

201 The Esplanade  
LAKES ENTRANCE  
03 5155 3055  
1300 855 260  
[www.bellevuelakes.com](http://www.bellevuelakes.com)

#### Lakes Sports & Community Club

38 Church Street  
LAKES ENTRANCE  
03 5155 3500  
[www.thelakes-scc.com.au](http://www.thelakes-scc.com.au)

#### Wyanga Park Winery

222 Baades Road  
LAKES ENTRANCE  
03 5155 1508  
[www.wyangapark.com.au](http://www.wyangapark.com.au)

#### Mulloway Fishing Charters

0427 943 154

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*A Polish immigrant wanted to apply for a driver's licence. First he had to take an eye test. He was shown a card with the letters CZWIXNOSTACZ. "Can you read this" the clerk asked. "Read it?" the Polish man replied, "I know the guy".*

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## Wear your jeans to work day

On Friday 10 August, staff of the tax division of KPMG, the accountancy firm, wore their jeans to work instead of their usual, formal attire. Each employee was asked to contribute \$2 or more to HLTTV in order to do so. Jane Rolfe, who is the wife of our Secretary and Treasurer Jon, is a KPMG partner and nominated HLTTV to be the beneficiary of this charity day. KPMG managed to raise a total of \$221.65 and we are allocating this amount to our rural and interstate accommodation program. HLTTV is very grateful to the KPMG staff who donated so generously to our cause and particularly Natalie Jessen and Maria Krelle who organized the event. Thank you so much to everyone who participated!

Perhaps more of our members could organise a similar day at their work to help our accommodation program?



## OTHER FUNDRAISING IDEAS

- Declutter and feel great - Sell those unwanted items online or hold a garage sale
- Socialise with family and friends - A special occasion - donations in lieu of presents

# GIVING AND RECEIVING

*As they say, this is my story.*

Just over two years ago I was in The Alfred, being kept alive by the wonderful medical team and the prayers of my family.

Apparently while I was still unconscious, I told my older son that I was having a transplant the next day - and, would you believe, I did!

Wendy said that some people can gain 20 kilos after a transplant, and I thought 'oh yeah'. But I am almost there. Thank goodness, I can blame the steroids and I have a wonderful excuse for buying new clothes.

Before my double-lung transplant I was on oxygen for about a year and nine months; it was so debilitating when I couldn't do the simplest things without gasping but now I can actually run.

Now comes the hard part. Just over thirteen years ago my beloved husband suddenly collapsed and was rushed to Emergency at the Austin. Scans showed that he had had an aneurysm = brain haemorrhage; the doctor showed me the catscan which showed how intense the damage was. Lenny was put on life support while they tried to do everything possible.

When Doctor Fay, the head of ICU, explained Lenny's condition in detail, she approached the subject of organ donation. Thankfully, though I was sort of in shock at that time, I remembered that we had discussed organ donation a couple of years before, while watching some show on TV and it was an 'easy' decision to make and thankfully my three adult children felt the same.

Donating your loved one's organs is something you never regret, knowing they are still helping others. And it is sort of comforting to receive a letter from the recipients.

**Kathryn Wright**



## **T-SHIRTS STILL AVAILABLE**

Profits from the purchase of the T-Shirts goes towards the Trust's fundraising for The Alfred's Transplant Clinic and promote organ donation – so we need your help.

Sizes S, M, L, XL and XXL. XS is available in a standard T-Shirt. Cost is \$25 plus packaging and postage.

If you would like to purchase one of our T-Shirts contact Jon Rolfe via email [secretary@hlttv.org.au](mailto:secretary@hlttv.org.au) or tel **03 9531 2234**.

# THE JOURNEY OF TWO PEOPLE THROUGH HEART FAILURE, LIFE SUPPORT AND TRANSPLANT

*Through the eyes of Karen (Carer) and Paul (Heart Recipient)*



## ***From Karen's Perspective:***

As the man I love lays there on life support – will he wake up? Will he survive this? Is he strong enough to face the next major challenge? And if he does, are we both strong enough to face the future and the changes in our lives? Our lives will never be the same again.

As the man I love struggles to breathe for three months after several diagnoses of asthma which occurred following the flu, after

being run down from excessive stress. It's 16 August 2010 and he's now on his way to hospital, being transferred from Sunshine to Footscray Cardiac Ward. The elite staff from both hospitals knew he would die without the assistance of The Alfred hospital.

My fiancé's blood pressure was decreasing rapidly. Within minutes he was being transferred to the Intensive Care Unit. Still awake and alert externally, internally he was suffering with

complete renal failure, his liver and kidneys were shutting down and his heart rate was increasing trying to fight it all. He looked so yellow. The cardiologist advises us that he needs to go to The Alfred hospital as they are the only ones who can save him. Save him? Yesterday he had stress and asthma, today he's fighting for his life with heart failure and complete renal shut down.

As I sit at the Footscray ICU in the waiting room, it's still not sinking in. I'm believing in hope and a positive outcome to get me through the night. I sit with him as he lay in Intensive Care, the cardiologist explaining to me that Paul is suffering from heart failure – what the hell did that mean! He's transferred to The Alfred ICU the next morning.

The long lonely drive home, my eyes fill with tears as I try to comprehend what is happening. I lay awake all night, my eyes are burning, my mind is racing, and I just want to be with him. As I slowly drift off to sleep, the phone rings, it's Footscray ICU staff advising me Paul has had a very steady night though he will be transferred to The Alfred - the only hospital in Victoria who uses the VAD (Ventriassist Device).

I drive to The Alfred and rush up to the Intensive Care Unit thinking 'This is so surreal - Why? How did this happen? Why Him? Will he live?' Reality hits... I could lose the man I love, the man





who has changed my life, changed my future, and the man who made me a better person.

After awhile the receptionist looks up at me, 'Karen, you can go in now'. I am taken down to his room and given explanation of the Intensive Care Unit whilst walking and what I would see. I arrive at his room and there he is, sitting up in bed, looking very yellow due to his liver failure, but looking so well – so alert. Why is he even here? He looks too well to be here.

I meet his Nurse, Kath – what an amazing woman. I knew right from the start this special lady would make a difference in our lives. I give Paul the biggest cuddle and hold him so tightly, what a relief to see him alive and appearing so well, other than the yellow colour.

I was new to this type of illness, it was all so surreal. I didn't have a thorough understanding of it, so I let all my questions fly, poor Kath, but God love her, she answered every question I asked. She provided us with so much more information. She was breathtaking, she instantly became our confidant, our support, and our most needed shoulder to lean on.

Kath's explanation was: Paul is suffering from Heart Failure, at the moment, he's in complete renal shut down and is a very sick boy. I said, 'but he looks so good'. She explained that he does look good externally but internally was telling another story. She convinced me that he was in the best place, with the best machinery/equipment and staff for his needs. On the medical monitor she showed me his heart rate and his pulse so I could understand

things a little easier. She clearly knew so much more, but gave us only a few numbers to look at. She also ensured to tell me, not to get hooked on the numbers, not to be become obsessed with them. She knew me so well, she instantly picked up that I was an emotional stress head and that Paul was a gentle relaxed beautiful natured man. My heart was aching for him, why wasn't I in that bed? Why him? I will never understand it. He constantly looked at me with his beautiful eyes and assured me he would be ok, assured me it's going to be tough but he would make it through 'for me'. I couldn't stop crying, it was such a harsh reality to be faced with.

After trying other treatments such as a femoral balloon to rest his heart which didn't have any positive effect, ICU Doctors knew Paul needed what they call an 'ECMO' machine, which would support and rest his heart.

After 10 days on ECMO (being the first patient in Australia awake on heart ECMO) the nurses begin to turn the settings down daily so that they can see how his own heart is now coping. On the tenth day Paul crashes. He is rushed off to surgery to have his LVAD - a mechanical heart that would act as his own heart until he gets a heart transplant. If he does not have this operation he will die.

From stress to flu, to asthma to heart transplant - so surreal. Paul comes out of surgery - a sight I'll never forget. I was with my Mum some 12 hours after the operation. He looked so ghostly. He was flat and freezing but I refused to wait until they had warmed him up to see him. It's a vision that will never leave my mind. He's now



a patient with a mechanical heart, awaiting a heart transplant.

I commence training on how his mechanical heart works, on what the various alarms mean and on what I must do if the controller fails. That is the most important part even though it very rarely happens. After training and three months of screenings and tests, he's on the list for a heart transplant on 17 December 2010 (my birthday).

#### ***From Paul's Perspective:***

Then we begin the waiting period, although surprisingly enough we are busy travelling in to The Alfred gym three days a week which is a 600 km round trip for the week, then followed by weekly clinic visits, doctor visits and weekly blood test to check INR levels. Thankfully as you get better the clinic and doctor visits become less frequent although the gym is a constant weekly routine. Some days it seems tough to go to the gym but it can be good for your motivation as you are with other people who are on the same journey as you and in some regards allow you some sense of

normality. You don't stand out and you are not the only one carrying around a bag that is your life support device. The shared experience makes you friends and we have made friends that will be with us for the rest of our lives. Plus it can be good sport stirring Lou up (my Physio - the lady who helped me gain my strength back and the ability to give myself the best chance of surviving the trials ahead and my eventual transplant operation). When you first begin at the gym it is hard, the strength and energy you once took for granted is gone. It is like starting all over again. You walk for fifteen minutes on a treadmill and have to sit down for fifteen minutes just to recover and riding the exercise bike is worse. At least the weights were something to be enjoyed. You can see benefits of your work and the weight you lift continually gets heavier and heavier. As you become stronger you can see the benefits of trying to get yourself into the best physical condition that you can. I told myself that this was the best way to recover from my operation. On a purely personal note I don't miss the six minute walk test one bit.

During this time you are so glad that you are still here that milestones such as birthdays and family gatherings take on greater meaning. As you get older you think that they are just another day and it doesn't matter if you celebrate them or not but when you are lucky to be alive, they certainly mean much more than they did.

There are set backs and usually they are out of your control. One day we were out walking and I was struggling a bit so Karen was holding my hand. I had to keep resting and as we were walking up the hill near our home I suddenly felt myself being thrown forward and I remember seeing my water bottle being thrown forward as well. I was in pain and bending over wondering what was happening to me when I was suddenly thrown backwards onto the road. Karen asked me if I was alright and said that she felt a shock go through her and I realised then that my defib had fired twice. I was too afraid to move because I thought it might go off again. Karen said she could feel the pain transferred through my hand to



her. Karen called an ambulance and I was transported into The Alfred. Tests later showed that my drive line was infected and caused my heart rate to exceed 180 beats a minute and that was what fired the defib. I can only describe it as like being kicked in the chest by a horse, and the second one was worse because I knew what to expect. The LVAD journey had many ups and downs, some days you feel great other days just terrible.

There is also fear, you are kept alive by batteries and electricity and without these the mechanical heart is just titanium in your chest and an extra weight. Luckily for us the power only went out once, and thankfully for a short time, but it brings home that you should always be prepared and have contingency plans.

We were told early on that most phone calls for transplants come between 8 pm and 5 am. It's funny, you go to sleep at night hoping the phone will ring in the middle of the night and being disappointed in the morning that you weren't woken up.

After 16 months on the LVAD I felt that my opportunity would never come and that I would not receive the gift of a transplant, but like all things they come when you least expect them.

On 18 November 2011, we were preparing for our tri-weekly trip into the Rehab gym at The Alfred, when at 7.18 am I got a phone call from the Transplant Co-ordinator telling me that 'this was my phone call' and that I had to be in at The Alfred by 9 am. I was both excited and nervous. I was excited that my life was going to change again, hopefully for the better,

but worrying what the outcome would be. I kept myself busy on the drive in by calling family members and letting them know. Karen was unbelievably calm and our 15 year old daughter was crying with tears of joy and also worries.

#### ***From Karen's Perspective:***

We arrived at the hospital just before 9 am. Paul was admitted and we were taken up to 3CTC. Once in the room Paul was gowned up, and his stats were checked, then I shaved his chest and he was really calm and just 'ready to go' and wanted to get in there. He was so ready, this was the moment he had waited for over the last 16 months. Then he was suddenly being taken to the operating theatre. We all went together in the lift with him and down to level one. I took photos and I got the last kiss. I was so scared this would be the last time I'd see him. I have been with him every day through this journey and I'd hope that we would take the next steps together as well.

As the hours passed friends and family, as well as other staff members that we had met along the way, supported me.

#### ***From Paul's Perspective:***

I am introduced to the anaesthetist and I am given the drugs that prepare me for surgery. I am given a time line of what they expect to happen but I am also aware that the operation can be called off at the last minute as well. I am told that the surgeon is expecting to begin the operation at around 11 am. Not long after 10 am I am told that there has been some delay but all is going well - but I will have to wait in

the operating area. One of the nurses tells me that it may not be until 1 pm, and can they get me something to read. Around 1 pm, my surgeon, Silvana walks in and says 'That's a first, my patient awake on the table and reading the paper'. Silvana informs me that they are ready to start and that my heart is on the way. Bec is with me and has been holding my hand and supporting me through the wait. She was wonderful.

#### ***From Karen's Perspective:***

Went to the park across the road. At 1.35 pm I got a call from the VAD Co-ordinator's phone. It was bloody Paul from theatre. Who the hell does that? My Paul. He was so beautiful. He said, 'I haven't got long. I just want to tell you I love you and I will see you soon'. There were tears and he was so happy and so calm. I couldn't believe that he called me. He is unbelievable.

Laurie came down to see me at 4.30 pm and said the heart has just arrived, Paul was really calm as he went to sleep. Reality kicked in once I realised that the LVAD would be out and that he would be on the by-pass machine, his only lifeline until the new beautiful heart would soon give him a second chance at life.

Before he went into the operation I told him that he had only one day to sleep and I was not going to wait as long as I did after the LVAD operation for him to wake up. He told me that he would wake up after a day and that he would see me soon. True to his word he was awake after one day, albeit a bit groggy.

Two days following his transplant I arrived in the morning and he is

sitting in his chair. He's been sick through the night but the heart is really good. He's only on one drug called Isoprenaline, which is normal. His heart is doing all the work on its own. Only problem is low blood pressure. Physio Kate wants it up over 50, after he stands it drops to the 40's. But it's around 62 when he's sitting or lying. He's doing unbelievably well.

He is responding well to treatment and although his first biopsy results were not as good as we had hoped he still feels good. A week later he has another biopsy and the results are much better and amazingly 15 days after transplant he is allowed to go home.

Since going home there have been some minor common setbacks with a couple of re-admissions into hospital but eight months post transplant Paul is a new man. The Alfred staff has given him a new life.

We are grateful to our donor and thank them for their gift in what would have been a very stressful time. We sent our donor family their letter, the hardest letter either of us has written. About eight weeks after we sent our letters we received a reply from Paul's donor's Mum. It brought tears to our eyes but we are forever grateful to a willing donor and courageous family.

If I could give one piece of advice I would say keep a diary. If you don't like what you read you can always burn it but I know Paul had no idea what I went through, and he reads my diary occasionally. I know it makes him emotional but he says it is good for him. He doesn't remember everything that went on and it helps him

piece it together. We also have a laugh at some of the things that he said while he was coming off the drugs, especially after the major operations. It doesn't need to be all doom and gloom. Also take pictures of your journey. You may not be able to look at them now but someday you may want too.

### ***On a sad note***



*Christmas Day 2011  
- Best of Buddies*

Paul and Craig Duncan were transplanted in the same week, went through VAD days together and then rehab together. They created a very special bond as did our families. Sadly we lost a very dear friend but we know he watches over us daily. We have beautiful memories and his wife Cathy Anne is the most amazing friend, her strength and courage is to be admired. We love her and her kids dearly.

### ***Great Day Out Getting Fit***

On a typical freezing day in Macedon, Victoria (though it was supposed to be summer), together with Anne Poole (Heart Recipient) with her husband Neal and their granddaughter Chloe and Eric Holt (Heart Recipient) and

his wife Ronis, we decided to follow the instructions of Lou Fuller, rehab and gym instructor by keeping fit, and went walking up to the Mount Macedon Cross.



*Paul, Anne & Eric*

Meeting at Paul's house, we drove up to the Mount and took a 3 kilometre walk together, through the beautiful serenity of the views of the Macedon Ranges to the Memorial Cross, returning to the starting point where we took in the scenery, enjoying beautiful Devonshire tea (don't tell Lou - ha!) - a well deserved treat.

A pleasant day out and a pleasant chat over tea and scones, reminiscing on the journeys but focusing on the beautiful long futures as dear friends who will keep in touch for many years to come.

Transplant friends, pre and post make very close bonds through shared experiences, never to be broken.

Never give up - life is too short, enjoy every moment and take your second chance as a beautiful gift.

***Love Karen Lowe and Paul Allen***

## The Dinner Party

### A film by Paul Cox

**Australian film writer** and director, Paul Cox, had a liver transplant on Boxing Day 2009. His experience of transplant inspired him to make a documentary, 'The Dinner Party'. The film was initially made as a thank you to the Austin Hospital transplant staff. It was then felt the film should be shared with a wider audience and was launched by the Director of the Austin Hospital Liver Transplant Unit, Prof Bob Jones AM and well known Australian actor David Wenham at the Austin Hospital on 7 August 2012.

The documentary is simply a dinner party, filmed at Paul Cox's house. All the dinner party guests are liver transplant recipients, who share their thoughts, views and experiences on camera. The result is a touching and honest account of the experience of liver transplant, and many of the shared experiences are familiar to other organ recipients as well. The film is now online <https://vimeo.com/49089259>

The audience for the launch comprised of Austin Hospital staff and a range of invited guests including our own representatives. A Q&A session followed with Paul Cox, Prof Bob Jones, and some of the documentary cast. In the Q&A session, Paul mentioned that in hindsight he regretted not including in the film the important role of the carers.

Paul is now working on a major film (for commercial release) relating to the story of an organ recipient and, as Paul said at the launch, he won't need a researcher for this character. The working title is Destiny and will star David Wenham. Paul said it will also be a love story!



*David Wenham and Paul Cox*

**TRANSPLANT AUSTRALIA**  
[www.transplant.org.au](http://www.transplant.org.au)

Keep up-to-date with Transplant Australia's activities such as the Australian Transplant Games, information about travel insurance and lots more.

The Greatest Gift  
Melbourne to Sydney Charity Run

Monday 27 August - On a lovely Melbourne morning we joined Transplant Australia in passing on our best wishes to Paul Bourke (a Sydney father of three young children) and his team of six runners as they left Federation Square after much planning to run non-stop from Melbourne to Sydney over four days. Paul's relay 'The Greatest Gift' was planned to raise awareness for organ donation in memory of his wife Suzette who tragically died of a brain aneurysm in December 2010. Suzette was an organ donor and her generosity helped six people with a second chance at life. Paul not only honoured Suzette's wish but has since dedicated his life to promoting organ and tissue donation and the importance of discussing your wishes with loved ones.

With the support crew and running relay style throughout the day and night they completed their journey on 31 August at Chipping Norton Public School, the school that Paul's children attend. Each runner completed approximately 125 km at an average speed of 6 min/km - a phenomenal effort.



*The relay team looking very smart*



*Paul ready for those collections*



*The support van about to leave ...*



*and so are the runners*

**The Annual General Meeting will be held on Tuesday 13 November 2012 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 the Trust during the last preceding financial year; and
- (c) to elect officers of the Trust and the ordinary members of the committee; and
- (d) to receive and consider the annual report prepared by the Trust in accordance with section 30(3) of the Associations Incorporation Act 1981 and whether to have them audited.

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](mailto:secretary@hlttv.org.au) no later than 14 October 2012.

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. Proxies are available on request from the Secretary.

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

- (a) made in writing, signed by two members of the Trust 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](mailto:secretary@hlttv.org.au), call on 03 9531 2234 or write to Secretary, HLTTV, PO BOX 25036, Melbourne VIC 3004.**

## Coincidences

On a recent trip to Bendigo Kathryn Wright saw two cars parked in the same row in a carpark with the stickers **Don't Take Your Organs to Heaven. Heaven Knows We Need Them Here.** It was the first time she had seen these car stickers.

Not too long ago I was travelling on the train and a couple of people who got on at the next station started discussing the map of The Alfred they had brought along. Should I say something or not! Turned out their relative was having a bone marrow transplant that day. On the way home while waiting for the bus I got chatting to a man about why we don't walk up the steep hill these days. When he mentioned heart problems I couldn't resist mentioning that I had had a heart transplant. He told me that two of his bowling team members had had heart transplants. I have a feeling these two might even HLTTV members! - *Editor*

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

Name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Donation \$ \_\_\_\_\_ (Donations 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' links to pay online.**



Heart & 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 of the Trust [ ]

I wish to receive my copy of 'The Circulator' newsletter by email: Yes [ ] No [ ]

RECIPIENT (Please complete information re Transplant Type, Operation, Month and Year)

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 Anniversary' each year Yes [ ] No [ ]

OR

PRE TRANSPLANT (Waiting List) .....

OR

CARER/OTHER/Supporter (Please specify) .....

Signature ..... Date.....

Membership for Pre Transplant patients is free. An annual fee of \$10 applies to all other category of members. An invoice for membership will be forwarded 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 donation. Donations over \$2 are tax deductible.

Please return this form to: Membership Officer Heart & Lung Transplant Trust (Victoria) Inc. PO Box 25036 MELBOURNE Victoria 3004

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

For enquiries: Email membershipofficer@hlttv.org.au



Heart & Lung Transplant Trust (Victoria) Inc.

AOO37327C/ABN 68 585 966 022

*"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 Transplant team,  
patients, recipients, their families and carers  
throughout the journey. "*

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If undeliverable please return to:-  
Heart & Lung Transplant Trust (Vic) Inc  
PO Box 25036  
MELBOURNE Victoria 3004

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*THE CIRCULATOR*

*Are your details correct?*