

# the Circulator

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

Second Quarter | 2013 | Issue No. 73

## Captain Heart

A Frank Interview



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# President's message

As the cooler months set in the Heart and Lung Transplant Trust (Victoria) (HLTTV) is busy with various fundraising initiatives designed to keep our Second Chance Accommodation Program running. Whilst, happily, we have a new agreement with Park Regis which extends our lease on the two 1 bedroom apartments for twelve months, this still means that many who need accommodation, such as that offered by Park Regis, do not have the ability to access it. In the past twelve months there have been around thirty recipients and their carers who have needed accommodation within walking distance to the Alfred Hospital. The need for fundraising for the Second Chance Accommodation Program as well as the broader fundraising objectives of the HLTTV, such as the provision of help for recipients and their families in need of it and the continued value adding to each clinic in terms of items needed outside their normal budgets,

## A note from the editor

A warm welcome to the second quarter issue of the Circulator, brought to you by the volunteers of the Heart Lung Transplant Trust (Victoria). I am keeping the 'L' plates firmly affixed for this issue! In this edition we have an eclectic mix of articles and information designed to keep you both informed and entertained. Our cover story considers the life of Frank who is on the precipice of making a decision about transplantation a path which is different for every one of us who makes that decision. Our brilliantly artistic

demand innovative approaches and Tour de Transplant (see page 16) is one such exciting concept. I urge all members to search out and ask all your extended family and networks for potential cyclists. We also have an upcoming Trivia Night, held on the 29th of June (see page 8) and it is these smaller, more easily managed fundraising events that we invite our members both to attend and to consider hosting in their own communities. My letter to each member regarding this sort of effort is being posted in the next few days. For almost twenty years now membership of the HLTTV has been kept at a nominal fee of \$10, however, for the first time in 20 years due to increased expenses in membership benefits such as the Circulator, postage, stationery etc., we have decided to increase the fee to \$15. We are looking forward to the launch of our new website so keep an eye on this address [hlttv.org.au](http://hlttv.org.au) to see the changes. Be well and take care.

David Hayne



editor, Camille, invites you to participate in the Hottie Challenge – a fundraiser for the Margaret Pratt Foundation. Camille also reports on the Film Life Project, a project whose overall aim is to increase awareness of the need for organ donation. Our former editor, Gaylynn, attended and reports upon her experience at the 2013 Service of Remembrance and Thanksgiving. Keep an eye out for all the exciting fundraisers that you have the opportunity to participate in, including the Tour de Transplant in 2014 and the Galipolli swim in 2015. We

introduce the lung transplant clinic's new dietitian Jacqui Anderson and feature a recipe designed to suit almost everyone. Thanks to those who provide valuable feedback, stories and ideas for The Circulator. Your submissions and suggestions are always welcome –

**Editor for June - Claire Stubber  
Belinda MacLeod-Smith  
Camille Condon**

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Cover photo: Ian Stubber

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

# Captain Heart (Cover Story)

*Most readers of this magazine are familiar with the vagaries of heart or lung transplantation but what of those for whom transplantation is a shadowy possibility? Frank Pecina is one such person. In his spare time Frank is a 'cosplayer', he spends weekends dressed in costumes and in this way helps raise money for various charities. One of his characters is Captain America (pictured) a fitting symbol of courage for Frank who, from birth, has faced chronic congenital (meaning present at birth) illness*

Frank is 40 years old, mild mannered and unassuming but his quiet and humble nature belies a courageous and resolute spirit. As a baby Frank presented some challenges to his mother starting with worrying episodes wherein he would suddenly turn blue. On these occasions his Mum would rush outside with him in the hope that the fresh air would revive him, and so it did. In the hope of preventing future 'turns' his mother would take her baby to the local hospital, using public transport to do so and try to explain, with her limited English, her baby's symptoms. The doctors never managed to witness these hypoxic incidents but eventually, at around seven months of age, Frank was diagnosed with congenital heart disease (CHD). Frank is unsure of the correct medical terminology to use to describe his particular variant of CHD and so states that he has two holes and two leaky valves.

At the age of five Frank required the



*Frank in 1978 at age 6 after his first open heart surgery*

first of three open heart surgeries he has so far faced in his life. This first hospitalisation, at the Royal Children's Hospital, was fraught for both Frank and his mother. His description of the memories he has of this time in his life are poignant. The little boy who was too weak to blow out the candles on the cake for his sixth birthday was able to gather enough strength to protest when agitated by the thought of the needles he faced daily that his Mum would be called in to the hospital to calm him down. He, of course, has no memory of the surgery in which his two leaky valves were replaced with plastic versions and unsuccessful attempt was made to patch up one of the holes. He remembers the hazy feeling of heavy sedative and analgesic medication but did not know until he was older that his Mum had received many calls in those first days post-surgery telling her to come in to hospital to see her son for the last time. He spent eleven days in intensive care before recovering on a ward. The day that he went home from hospital Frank had become so desperate to leave that he staged a protest. Not understanding the word 'discharged' he was under the impression that he had to stay and

so lay down in front of the taxi in which he thought his Mum was leaving alone. He struggled as his Mum picked him up and placed him on the back seat. He carries with him the sense that so much time had passed that the formerly trimmed grass in his front yard had grown to chest-height. Future overnight stays in hospital for Frank were accomplished only with the bribe of toys.

Frank's life had to be lived within the constraints of his physical condition, he could not run and was continuously short of breath. Still, he adapted and worked out ways to belong in a world where physical prowess in boys was prized. He figured out children two years younger were on a par with his physical ability and so he befriended them. In this way he also enjoyed a privileged position of seniority and was not teased for his inability to keep up with his peers.

Life continued with these restrictions and at nineteen years of age, when he had stopped growing, Frank had his second open heart surgery. This time patching of the holes achieved a ninety percent seal and the valves that had been replaced with plastic were now replaced with porcine valves. After this operation Frank was told

## Captain Heart (cont.)

that he could increase his level of exercise and since he could function with a near normal exercise capacity he could live a 'normal' life. This meant for Frank that he could attend hospitality and commercial cookery courses and fulfil his dream of becoming a chef.

Worried that employers would assume that CHD was a barrier to employment, Frank set out to prove that he could do better than an employee without CHD. He started volunteering as a dishwasher in a local pizza shop, making clear that he could cope with the physically demanding work required of a chef. His strategy worked and he managed to juggle both a full time, seven day a week job as well as a part time job between 1999 and 2002.

In late 2002 signs that Frank's heart was not as robust as it should be began to appear. He was coughing regularly and regurgitating any food he consumed. He had noticeable distension from fluid retention in his abdomen and legs. He knew that there was something seriously wrong but even though he was ending up in the emergency department at least three times a week, investigations proved inconclusive. During this time, consistent with his work ethic, Frank was still attending work but was being sent home or to E.D. every day. When he eventually managed to see a cardiologist he was not capable of walking more than 750 metres without rest. He was found to have fluid in his lungs and an aortic valve that had been stretched to three times its normal size.

In December 2002 he had the excess fluid drained from his lungs and his legs, he lost twenty kilograms from a combination of this procedure and his persistent regurgitation of food. Frank was discharged on the

24th of December and told that he had four months to live without an operation. The nature of that operation was uncertain, it was dependent upon what the surgeons



*Frank in 1991 after his second open heart surgery*

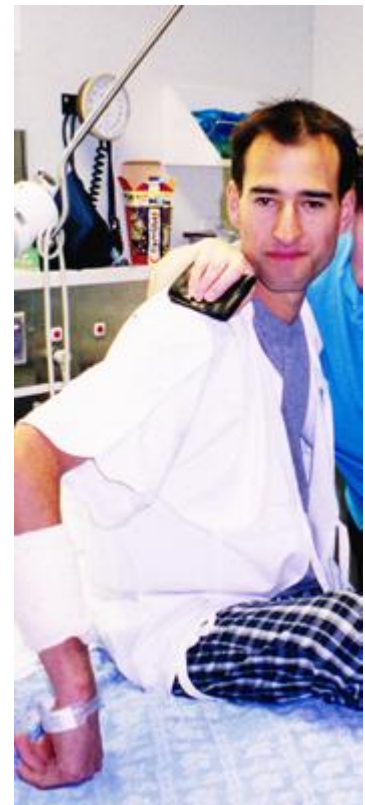
found when they once again opened his chest. Frank was given a fifty percent chance of surviving this third open heart surgery.

In a nine hour operation surgeon, Mr. Peter Skillington, had trouble gaining access to Frank's grossly enlarged heart because there was so much fluid surrounding his heart. Once the fluid had been effused Frank's heart began beating with a normal rhythm. The holes in Frank's heart were one hundred percent sealed. The porcine valves that had been implanted in the previous operation were again replaced, this time with metal and synthetic valves, a step further Frank says in his transformation into the Six Million Dollar Man.

When Frank recovered from this surgery he was told that the surgeons had performed the last major operation that his heart would be able to endure and that in future

his only option would be heart transplantation.

Frank is philosophical about the prospect of heart transplantation. When the possibility was first



*Frank in 2003 after his third open heart surgery*

raised he was so grateful that he had survived an operation from which he expected never to awaken that he had little thought for some future procedure. Even now Frank's approach is calm and reasoned, he is hopeful that by the time his transplantation is needed surgical and pharmacological advances will mean that the operation and its aftermath are fairly minor. He is aware that currently Australia has a high success rate for transplantation and is comforted by that fact. High profile cases such as that of Fiona Coote have given him faith in the practice of heart transplantation and success stories such as hers have made the prospect of transplantation easier to face. Frank is already planning for life after transplantation and although he loves his career as a chef is transitioning from this to a desk job so that he is better able to handle

## Captain Heart (cont.)

the physical demands transplant may place upon him.

Despite his first traumatic hospitalisation and all the medical intervention Frank has faced in life he conveys deep affection for the medical staff and the experiences that he has had in the hospitals in which he has had his operations. At the Royal Children's Hospital in 1991 when he had his second open heart surgery Frank remembers that the nurses made his stay 'paradise' and he felt as though he was attending a holiday camp. It was this experience which allayed his fears about hospitals. He enjoyed the privileged position of being a child whom the other children looked up to and relied upon for advice. In 2003 his humour and kind heartedness combined with his sick heart so that he was the favourite patient in both a personal sense and a medical sense. He had so many student doctors wishing to listen to his physically unusual heart that a poster was made requesting a \$2 donation per examination. Frank raised \$2 from one indulgent student and this grand sum was donated to the nurses to put towards their Christmas party. When Frank was wheeled out for his high risk surgery the nurses formed a guard of honour for him. Captain America is Frank's chosen superhero representation, an exaggerated version of Frank and the way he has lived his life. Captain America's transformation from the ordinary and somewhat wimpy Steve Rogers to a superhero is thanks to a super serum that infuses him with an extraordinary strength of body and mental character. Frank's 'super serum' is his congenital heart disease a seeming affliction with which Frank would not be without as he understands it to have shaped his character and to have given him a unique strength

of mind and willpower. Captain America is a gentleman whose old school values Frank feels sum him up. In his costume Frank volunteers his time to raise money for charity he feels that raising money in this way is rewarding and that the costume doesn't put people under pressure to donate. One of the most enjoyable parts of his charity work is the opportunity he has to interact directly with sick children a chance, he says, to demonstrate and to tell the children that a normal life can be had post-surgery. Charity work also gives Frank the chance to give back, an important notion for Frank who is aware that it was the charity work of others' that contributed to the research funding that has kept him alive. Frank says 'I have the same heart as Captain America' and it has served him well and whatever challenges he may face rest-assured that he will face them bravely, honestly and wisely.



Frank today



'Brett Sparrow'

If you are interested in costumed members of the Melbourne Costume Group appearing at your next fundraiser please contact Anne O'Reilly or Jen Sasson at: [cosmelbourne@gmail.com](mailto:cosmelbourne@gmail.com)

## 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 solutions 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 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.

### 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.

# The Film Life Project

Our editor Camille Condon reports on *The Film Life Project* and *The Hottie Challenge*. If you are inspired by these creative ventures why not take a look at Camille's fantastic online shop and blog: <http://curly-pops.blogspot.com.au/>

The FilmLife Project is an annual festival that teaches the art of filmmaking to young people between the ages of 16 and 28, while exploring and capturing stories about organ donation. The specific aim is to raise awareness about organ and tissue donation by 'having the chat' and knowing your loved ones wishes.

This year, free weekend workshops were run in Melbourne and Sydney in February. The young filmmakers were taken through the following processes:

- Pre-Production:  
Scriptwriting, Locations, Storyboarding, Drawing
- Production:  
Equipment Usage, Collaboration, Identifying Roles
- Post Production:  
Filmmaking Software and Editing

During the weekend, they were also given the opportunity to meet with both donor families, and transplant recipients.

Each three minute film had to engage with the theme that had been given for DonateLife Week 2013 – "Make your wish count. Discover, decide and discuss organ and tissue donation"

A FilmLife Blogging competition was also held in conjunction with the film festival. Bloggers were asked to write a 300-800 word blog



*A still from the winning film 'Somebody That I'll Never Know' by Brooke Huuskes*

post inspired by the DonateLife Week 2013 theme.

The FilmLife Festival Screening night took place in April. Films were screened in unison at the Information and Cultural Exchange (ICE) in Sydney and at the Footscray Community Arts Centre in Melbourne. The event was also live streamed on the internet for those who couldn't make it to either venue.

The filmmakers were all novices and only had two weeks to complete their projects. The quality of the films was outstanding and the judges and audiences were very impressed.

At the end of the screenings, prizes were awarded for the Best Film, Best Use of Theme, Commended, and Best Blog Post.

The winning film was an amazing Gotye parody named 'Somebody That I'll Never Know', by filmmaker Brooke Huuskes. Brooke is a transplant recipient herself, after receiving a kidney from her father. It features the actors playing Kimbra and Gotye. Kimbra gives permission to donate Gotye's organs as they've already had the chat and know each others' wishes.

The film has had nearly 29000 views on You Tube.

Another of the films, 'Can You Imagine' by David Dixon, stars our very own HLTTV Membership Officer, Louisa Walsh, and her partner Sean. It asks the hard questions about whether you can imagine doing things for the very last time, and whether you can imagine making your last wish count.

To learn more about the FilmLife Project or to register your details for next year, just visit the FilmLife website - <http://filmlife.com.au/>

To view the films: <http://filmlife.com.au/watch-all-of-the-2013-films/>

To read the blogs: <http://filmlife.com.au/2013-filmlife-blog-comp/>

The FilmLife Project is the brain child of The Groundswell Project and was funded by the Organ and Tissue Donation Authority



# The Hottie Challenge

The Hottie Challenge is the creative brainchild of Robyn Steel-Stickland and Prue Barridge from Open Drawer Art Textiles and Learning Centre in Hartwell.

This is the second time that the challenge has been run. In 2011, almost \$4000 was raised and donated to the Margaret Pratt Foundation.

The Margaret Pratt Foundation Heart Lung Transplant Trust is a registered charity whose aim is to encourage, develop and maintain Australia's world class expertise in the field of organ transplantation by supporting research that addresses the problems faced by children and adults after heart and lung transplant.

The aim of the research must be to improve the outcomes for heart and lung transplant recipients.

The foundation provides funds for the Alfred Hospital staff who are working on research into chronic rejection of transplanted lungs. To date, in excess of \$850,000 has been donated.

The aim of the challenge is to make a Hottie Cover (Hot Water Bottle Cover) using any artistic or creative method possible. The

Hotties will be exhibited in the upstairs gallery space at Open Drawer from Friday July 5th until Sunday July 28th 2013. There will be a Gala Opening on Sunday July 7th from 2-4PM.

During the exhibition, each Hottie will be available for sale, with all monies raised being donated to the Margaret Pratt Foundation Heart and Lung Transplant Trust. Visitors can also vote for their favourite Hottie by donating loose change.

This year's event has already attracted more entries than the previous with over 150 talented creative people signing up.

If you're feeling a little creative, then there's still time to enter the challenge. Just download the application form and follow the simple instructions. The entry fee is \$5 and a Hottie Kit will be mailed out to you containing the paper pattern, a Hottie Hanger (so that they can be hung on the wall for the exhibition) and all the details. Entries must be in by Friday June 23rd.

[http://www.mprattfoundation.com.au/images/documents/hottie\\_challenge\\_2013.doc](http://www.mprattfoundation.com.au/images/documents/hottie_challenge_2013.doc)

If you don't have access to a computer to download the application form, then just call Robyn or Prue at Open Drawer on (03) 9889 7227 and they will happily mail you a kit.

The 2011 exhibition was wonderful

and I'm sure 2013 will be even better!

Open Drawer - <http://opendrawer.com.au/>

1158 Toorak Road Camberwell (Hartwell Village) 3124 (Mel 60 C6)

Tram No 75 - Stop No. 52

Train - Burwood Station - Alamein Line

Margaret Pratt Foundation - <http://www.mprattfoundation.com.au>



*Above: some of this year's entries for the Hottie Challenge*

*Top: entry from Amanda Hickman*

*Middle: entry from Cintia Gonzalez*

*Bottom: entry from Shelley Husband*

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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 Belinda, 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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## Welcome

There is a new dietitian attached to the lung transplant outpatient clinic on the 5th floor. Jacqueline Anderson is a Senior Dietitian who works in the Cystic Fibrosis and Lung Transplant Unit who consults with patients who are both pre and post lung transplantation, she also works with other Dietitians in the Respiratory Inpatient Unit. Jacqueline has had over fifteen years experience as a Dietitian and has worked at the Alfred Hospital for four and a half years in total. She returned to the Alfred in September 2012 after two years in the UK. If you feel that you would gain benefit from a consultation with the Dietitian, this decision must be made in consultation with your doctor who can refer their patient, as and when appropriate, to a Dietitian.

## Calling all Brainiacs



The Heart Lung Transplant Trust of Victoria are holding a trivia night to raise funds for the Second Chance Accommodation Program

The trivia night is happening on the 29th June 2013 at the St Silas Church Hall, 99 Bridport St W, Albert Park, from 7pm. BYO Drinks, snacks and gold coins for raffles and fun along the way!

Tickets are \$15 ea or \$100 per table of eight book your table through [trybookings.com](http://trybookings.com)

This venue has been made available to the HLTTV through the generosity of the St Silas Parish and the Vicar Ray McInnes

## Winter Warmer Soup



*This is one of those wonderful adaptable recipes, it is very forgiving and quick to make. Lovers of heat can increase the spices and the number of chillies. Dietitian Jacqui Anderson suggests that those with Cystic Fibrosis need not use salt-reduced stock and can use more olive oil to cook the onions and garlic. If you have never used lentils before, red lentils are a great place to start, they require no soaking and cook in just 20 minutes.*

### Ingredients

- 1 brown onion, finely sliced
- 2 cloves of garlic, crushed or diced finely
- 2 tbs olive oil
- 1 chilli finely diced (optional)
- 2 tsps each of garam masala/ cumin/ turmeric/ curry powder/ coriander seeds/
- 1 can of tomatoes
- 1 L salt-reduced chicken or vegetable stock
- 1 cup red lentils
- 1 cup of diced fresh vegetables e.g. carrot, celery, capsicum, kale
- some fresh coriander leaves if you have them

### Method

- cook the onions and garlic in the oil on a low heat until soft.
- add the spiced and stir for a minute until fragrant
- add the tinned tomatoes, stock, lentils and the vegetables
- simmer for about 20 minutes until lentils and vegetables are soft
- stir in coriander at the end

## Allan Browne OAM

Sincere congratulations are extended to Allan Browne by the Heart Lung Transplant Trust (Victoria) for the recognition he received on the Queen's Birthday Honour List awarded an OAM on the 10th of June 2013 "for service to music as a jazz musician, and to the community". Allan is a single lung transplant recipient and a Jazz drummer Bandleader, composer and poet who formed the Red Onion Jazz Band in the 1960s. He currently leads his jazz band The Rascals and collaborates with a multitude of other musicians. He has been the past recipient of awards such as the Australia Council's Don Banks Award, the Hall of Fame Award at the Australian Jazz Awards and in 2010 the Australian Jazz Bell Award for the Best Classic Jazz album.

## Fast Facts

### HLTTV Second Chance Accommodation Program

\$10,350

...the average full cost to stay in a hotel close to The Alfred.

\$1,350

...the amount payable by families paying a nominal \$15 per day in the Second Chance Accommodation Program.

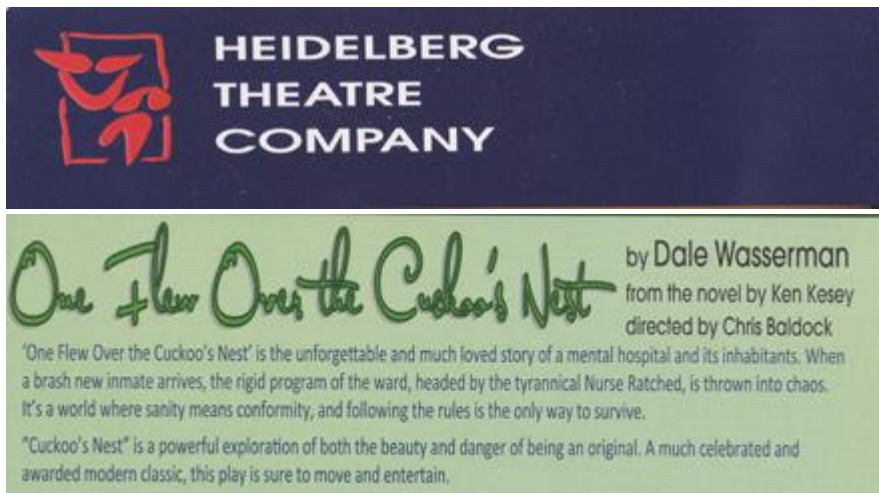
The nominal fee, along with a State Government rebate is paid directly to the Park Regis Griffin Suites, with HLTTV making up the balance.

\$19,200

...the amount HLTTV has invested so far for two apartments during 2012.

While that's the best we can do for now, we predict we'll need at least eight apartments to meet the expected need for 2013 and beyond.





## Opening Night Fundraiser

Proceeds to the Heart & Lung Transplant Trust (Vic) Inc  
Second Chance Accommodation Program

When: 8 pm Thursday 12 September 2013

Where: Heidelberg Theatre Company Inc  
36 Turnham Avenue, Rosanna Vic 3084

(opposite Rosanna Railway Station Melway ref 32 A1)

Cost: \$25 per ticket

Enquiries/Bookings (by 1 August 2013):

Gaylynn Pinniger Tel 9458 2603 [gaylynn.pinniger@gmail.com](mailto:gaylynn.pinniger@gmail.com)

## Congratulations!!!

To our HLTTV Secretary, Jon Rolfe, his wife Jane and two year old daughter Isabelle on the new addition to their family, baby Samuel James Rolfe, born 2:16pm on April 29th weighing in at 8lbs



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



## Can we help you get together?

While the HLTTV is committed to regular events here in Melbourne, we're keen, and curious, to know if our many regional, remote and interstate members require support with their social events.

A sense of community, and having a network of people who understand what you're going through can be a source of great comfort while on your transplant journey.

What can we do to help make this happen where you live? Can we promote a local event here in the Circulator, or our website? Can we liaise or advocate on your behalf with your regular clinic location?

It's part of our vision to support all of those involved with or in need of a heart or lung transplant. Let us know what we can do for you.

Email | [president@hlttv.org.au](mailto:president@hlttv.org.au) or contact us using our website at

[www.hlttv.org.au](http://www.hlttv.org.au) or visit us on Facebook - just search for Heart and Lung Transplant Trust and make sure to "like" the page to stay in touch with the latest news and events.



# Gallipoli 100 Year Swim Challenge

In August 2015, HLTTV will celebrate the 100th anniversary of Gallipoli with an ocean swim across the famed Dardanelles Strait that separates Asia and Europe.

## The Event

A proposed endurance swim event to coincide with the 100th anniversary celebrations of the Australian battle of WWI at Gallipoli.

Known as the Hellespont Swim this is an existing event that occurs on the Turkish National Day every August. The event is managed by Swim the Dardanelles Competition Committee.

The swim is approximately 4.5kms and commences at the ancient town of Eceabat on the European side of the straits and finishes at the naval fort in Çanakkale on the Asian side of the straits.

The event sees one of the busiest shipping lanes in the world closed to traffic for the annual 'Victory Day' race between two continents as participants swim from Europe to Asia. This is a unique opportunity to swim across the Dardanelles. Entries are strictly limited.

In 2012, only 350 swimmers participated.

## Tour

The tour is fully managed and coordinated by Cousins Travel.

## Limited Places: Expressions of Interest

The 2015 Gallipoli Swim is limited to just 40 participants. This includes both the swimmers and the partners/ supporters. Accommodation is twin-share (with an option to upgrade to single, if desired). Places therefore are at a premium. Expressions of Interest, while not binding, are encouraged in order to secure your place.

## Gear & Kit

All participants are required to provide their own gear and equipment. In extreme years a light wet suit maybe required. HLTTV will provide each member of the touring party with a commemorative pack which includes framed certificate, medal, polo shirt, cap, towel and drink bottle.

## Tour Costs

Tour cost \$1,990 pp twin share (land only)

## Fundraising Target: \$9,600

All participants are expected to raise donations, which are fully tax-deductible. While there is no maximum, each participant is encouraged to raise donations that would support.

Why \$9,600? Well this will provide for one apartment to give an apartment home close to The Alfred for one year, thus saving 4 transplant families!

## How to raise \$9,600

HLTTV will work closely with all participants to help them in the endeavours to raise funds for an amazing cause. Some participants might like to combine resources and put on a Trivia Night, Film Night or Dinner. We find the best way is to break it down into simple pieces. Most companies will sponsor employees and match \$ for \$ what they raise.

• Make a personal donation of \$1,000 = \$1,000 • Invite 20 friends to donate \$200 each = \$4,000 • Ask your work company to match you = \$5,000

[www.gallipoliswimchallenge.org.au](http://www.gallipoliswimchallenge.org.au)

We are asking members to spread the word about this event amongst friends, family and colleagues. If they have questions or wish to offer expressions of interest please contact our Secretary, Jon Rolfe, on 0432 845662 or e-mail

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



## Tour Inclusions

- Transfers Istanbul/ Çanakkale /Istanbul
- 6 nights accommodation 4 star hotels
- Breakfast daily
- Walking tour in Istanbul
- Guided Topkapi Palace tour (Harem entrance not inc.)
- Bosphorus cruise
- SwimTrek package inc. race entry,
- Tour of Gallipoli
- Tour of Troy
- Single supplement \$595pp

## Quick Facts

The swim is scheduled to take place in August 2015. The tour will be limited to 40 places.

Depart: 20 August 2015 (TBC)

Return: 27 August 2015 (TBC)

Nights: 6

Length: 4.5kms

Max Participants: 40

# 2013 Service of Remembrance



*Former editor of the Circulator, Gaylynn Pinniger reports on this year's Service of Remembrance and Thanksgiving, an annual service held to commemorate and give thanks to the previous year's organ donors.*

The Service is conducted under the auspices of DonateLife, the Victorian Organ Donation Agency. It was held in RMIT's Storey Hall Auditorium in Swanston Street, Melbourne - the same venue as last year. The beautiful flower arrangements in pinks and burgundy were stunning.

The Service began with the Royal Melbourne Hospital Staff & Volunteer Choir singing Count on me by Bruno Mars. During the Service the Choir sang two other songs - *Arms of the Angel* by Sarah McLauchlan and *I can see clearly now* by Jimmy Cliff.

The Words of Welcome were by Prof Stephen Cordner, Professor of Forensic Medicine, Monash University Director of the Victori-

an Institute of Forensic Medicine, which incorporates the Donor Tissue Bank of Victoria.

Once again as a symbol of remembrance a representative from the donation and transplantation sectors lit the candles.

The Medical Community was represented by Mr Graham Starkey, Liver & Intestinal Transplant Surgeon at the Austin Hospital. He explained how he is often thanked after someone has a transplant but it is the donor families that are the ones who he has the most admiration for.

In honour of donors a very moving poem written as a tribute to a sister was shared.

On behalf of recipients, Martin explained that he only learned of his heart problem during a routine work health check. Thanks to receiving an aorta valve he is now back enjoying life with his family.

Abbey's father gave a power point presentation showing her life from birth and then how after a short time she struggled with a rare liver disease. At the age of one Abbey was unable to crawl or walk because of her enlarged stomach. Life was slipping away. How wonderful it was to meet Abbey (now in Prep at School) when she came onto the stage to join her father. All thanks to a donor family.

A photographic acknowledgement of the people who donate and those who received the gift of a donation took place, followed by the cutting of the cakes by a donor family and recipient as a reminder of being part of one journey.

Lighting of candles is a special way to remember loved ones and for those who are thankful to be recipients. Cards to write messages were once again provided and collected in mini books. Large volume Books of Life were available for perusal in the foyer.

Afternoon tea followed the Service. Thanks must go to Gai Di Blasi who has been the organizer for many years with the help of volunteers. A wonderful chance for everyone to mingle. It was also a chance for some of our members to catch up.

A special thanks to the members of the 2013 Planning Committee:

Michelle Skinner - Donor Family Support Coordinator  
Annette Smith - Kidney Health Australia  
Melissa Brouwer, Dana Pedersen and Nicole Gauthier - DonateLife  
Susan Dickie - Donor Tissue Bank of Victoria  
Prema Finn - Lions Eye Donation Service  
Anne Shipp - Royal Children's Hospital

The Remembrance Service is held on the last Saturday of May each year.

VALE

## Patrick James Killeen

5 August 1946 - 15 April  
2013



Pat was born in Prahran, Melbourne and grew up in Commercial Road.

In the early 70s he started working for Grazcos Wool Classing where he travelled around Australia classing wool on large sheep stations. Pat was posted to Hay NSW where he met Martha who was working in the Grazcos Office. In 1973 Pat was appointed Manager of Grazcos in Bairnsdale. He married and had two children Aaron and Rhani. He joined Apex and made lifetime friends. And Bairnsdale is where he stayed.

In the early days when not travelling he loved surfing. He and his mates would head down to Torquay and surf the big waves at the infamous 'Bells Beach'. Pat enjoyed boating and for many years over summer, weekends were spent with five other families camping on the Gippsland Lakes.

Pat travelled to China in 1987 where he toured around and also

in 1989 he travelled to India. In June 2001 he travelled to London to visit his son Aaron.

Pat fell ill on 5 April 2010 (exactly three years to the day of his death). He was transferred to Austin Respiratory. On 19 April 2010 he was told that his lung disease was totally unpredictable and he would be referred to Dr Snell at The Alfred Lung Transplant Clinic. On 24 May Pat started evaluation tests for a lung transplant. Lots of tests were undertaken during that week, including lung function on 27 May (he couldn't give a proper reading as his breathing had deteriorated so much in that last month). On 28 May 2010 Pat was due to go back to Bairnsdale in the afternoon. That morning (10 am) he was told there was a 30% chance a lung was on the way that would suit him. At 6 pm that day they started to operate and he was transplanted with a left lung.

Rhani said that her Dad was given a second chance in life receiving his transplant within only hours. 'We knew he wasn't ready to go!!' He survived to see his three grandchildren who brought him so much happiness and amusement. 'He showed us all an enormous amount of strength and courage as he fought, and most of all he showed us miracles really do happen.'

*Our sincere condolences are sent to Pat's family. His family asked for donations in lieu of flowers to be given in support of The Alfred's Heart & Lung Transplant Unit.*



### 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.

# Diary dates, reminders and events

July						
Sun	Mon	Tues	Wed	Thur	Fri	Sat
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			
August						
Sun	Mon	Tues	Wed	Thur	Fri	Sat
				Booking deadline for One Flew Over The Cuckoo's Nest 1	2	3
4	5	6	7	8	9	10
11	12	HLTTV Committee Meeting 13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31
September						
Sun	Mon	Tues	Wed	Thurs	Fri	Sat
Father's Day 1	2	3	4	5	6	7
8	9	10	11	One flew over the Cuckoo's Nest Fundraiser 12	13	Federal Election 14
15	16	17	18	19	20	21
22	23	24	25	26	27	28

## A reminder from the membership officer - **Membership Renewal Due in June**

Make sure you stay a part of the transplant community by renewing your subscription. HLTTV membership provides you with relevant news, events and information. It's a great way to stay in touch, and support the work of a passionate organisation. Membership forms are available online, or see page 15 of this edition. Our membership fee has had to increase this year to \$15, rising publication and processing fee costs have prompted this first fee increase in almost 20 years.



**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 particularly easy to do using [www.givenow.com.au](http://www.givenow.com.au)**

**Simply visit <http://givenow.com.au/hlttv> and follow the prompts.**

# Transplant anniversaries - we wish you many more

## April

### Heart:

- Allan, 1994
- Les Doughty, 2011
- Bill Saunders, 2010
- William Vickers, 2003

### Lung/s

- Gwen Ledwidge, 2009

### Heart and Lungs:

- Jose Lopez, 1990

## May

### Heart:

- David Cripps, 2006
- Neal Pearson, 2011
- Tuariki Rua, 2009
- Peter Slatter, 1996
- Henry Smeets, 1996
- Kevin Williams, 2003
- Bruce Wood, 2003
- Richard Metzke, 2003

### Lung/s:

- Antonio Ferraro, 2008
- Doris Hogben, 2010
- Patrick Killeen, 2010;
- Tony Matteo, 2004

## June

### Heart:

- Marc Bainbridge, 2011
- Christine Liszczak, 2008
- Maarit Moilanen, 2010
- Anne Poole, 2011
- Richard Rolands, 1992
- Jim Spooner, 2004
- Laszlo Toma, 2006

### Lung/s

- Shirley Hodgson, 2008
- Malcolm Knight, 2009
- Barb Maywald, 2006
- Nancy Scaringi, 2009
- Vanessa Scott, 1999

## 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.)

<b>Lung/s</b>	Month	[ ]	Year	[ ]
<b>Heart</b>	Month	[ ]	Year	[ ]
<b>Heart &amp; Lung</b>	Month	[ ]	Year	[ ]
<b>Other (please specify)</b>	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.hlty.org.au/> and follow the 'Membership' links.

For enquiries email [membership@hlty.org.au](mailto:membership@hlty.org.au)



### About the tour

In March 2014, the Heart and Lung Transplant Trust (Victoria) Inc. (“HLTTV”) will conduct the inaugural nine day cycling challenge, Tour de Transplant. The challenge will raise much needed funds for the Second Change Accommodation Program. The route will take us from Melbourne to Geelong, where we start our journey and up through Ballarat, Bendigo, Shepparton and to the border at Albury. From there participants ride south east crossing over the Victorian Alps to Gippsland before the final stretch to Melbourne.

The length of the ride and route are incredibly significant, as each kilometre equals one of the 1,100 Victorian heart and lung transplant recipients, while the route itself directly visits areas and towns where there are many transplant beneficiaries.

The Tour will be led by Australian cycling legend Phil Anderson. This extraordinary event will be a once in a lifetime chance to spend a week in the company of one of Australia’s true sporting champions. All expenses, covering food and accommodation are included in the registration fee

with participants expected to raise additional funds for HLTTV. Numbers are strictly limited to a maximum of 25 riders

### About tour legend Phil Anderson

Phil Anderson OAM is one of our cycling heroes. He won gold in the 1978 Commonwealth Games, turned pro and joined the intensely competitive professional European road circuit with a career spanning 16 years and culminating with another Commonwealth gold in 1994, the year of his retirement. Anderson is well known for being the first Australian (and first non-European) to win the prestigious yellow jersey in the Tour de France. His daring challenge of the French favourite, Bernard Hinault and his exploits on the road, are stories full of pain, fierce determination and excitement. Ultimately Phil Anderson won the yellow jersey 11 times and rose to number one in the world.

Costs  
Participants will be required to pay a registration fee of \$3,500 which covers the cost of twin share

accommodation, breakfast, lunch and dinner for the tour.

The fee is not considered a donation and therefore is not tax-deductible. Your fund raising targets will be set much higher with a minimum expectation that each participant will raise a further \$5,000 for HLTTV, which will be tax deductible. HLTTV will assist participants to achieve this aim.

### How Can You Help?

We are asking all our members and readers of this edition of the *Circulator* to please think of all their contacts that may be interested in an exciting opportunity to be part of the Tour de Transplant and show them this or one of the Tour brochures,

Want to get in contact?  
President: David Hayne | Mobile:  
0418 148 919  
[president@hlttv.org.au](mailto:president@hlttv.org.au)

