



the Circulator

Issue No. 71

4th Quarter 2012

www.hlttv.org.au



JON ROLFE Double Lung Transplant and 'Alcatraz Escapee'

page 18

Season's greetings and best wishes for the coming year



WENDY RETIRES AFTER 19 YEARS page 5

2013 DIARY DATES

12 February

Special General Meeting and Committee Meeting

24 Feb-3 March

DonatLife Week 2013

Sunday 24 March

Easter BBQ at Fawkner Park

Another Reminder from the Membership Officer

Your membership is valued. Subscription renewals are now well overdue. Please complete the membership form on page 23 and return as soon as possible or renew online at hlttv.org.au



**TRANSPLANT
ANNIVERSARIES** page 8

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(details in the next edition)

Do you have the skills to take on the role of HLTTV Treasurer?

Do you have the skills to take on the role of HLTTV Treasurer?

Jon Rolfe has been undertaking the role of both Secretary and Treasurer but it is now necessary for someone else to take over the role of Treasurer. The accounting reports are up-to-date and all procedures have been documented.

If you would like to discuss this role please contact Jon on (03) 9531 2234 or mobile 0432 845 662

From the Outgoing Editor

After a number of years as Editor it was time to 'pass on the baton'. It was very pleasing that three members have come forward to volunteer to take on the role and a new team is being formed. This is just to introduce each of them. I am sure you will hear more later on.

Belinda McLeod-Smith is Carer for her husband Mark who is waiting for a heart transplant. She has just relocated with her family to Melbourne from Adelaide.

Claire Stubber is a heart and lung transplant recipient and you may recall from a story in The Circulator earlier this year (Issue No. 69) she met her husband Ian, who has had a double lung transplant, during their transplant journeys. Claire and Ian are from Perth and have now settled in Melbourne. Claire has done research on the history of solid organ transplantation. Ian is a Photographer.

Camille Condon is a pre lung transplant patient and runs her on-line business CurlyPops from home.

I 'take my hat off' to the Editors who in the early days didn't have the ease of everyone having access to email. When I met Ana Goutzamanis she said she was so relieved when someone else took over the Editor role being undertaken by her and Roxanne De Carta - and perhaps I feel the same - but I will definitely miss the interaction with so many people.

How did I get involved in the first place. My husband and I, not long after my heart transplant, decided to attend the Trust AGM. I came away having volunteered to become Minute Secretary after the Secretary, the late David Lawley said he had a hearing problem. David was both Secretary and Editor of The Circulator. He did all of the work for a long time. Kevin Williams helped

by taking on the role for a short time. When David needed a break, the late Glenn Leno volunteered just to help out David - and that's when I came along to help out Glenn and have continued ever since!

Of course I couldn't have done the job of Editor without your contributions, and without the help of my husband Ross who came to the rescue with the technical side in each and every edition. John Bisiach and Claude Turco in the past, and of late Diana Almonte, have helped with the preparation for mailing. The design work this year has been done by Keith O'Donnell and Louisa Walsh has been preparing the address labels. Art57 has been our long time Printer and Helen has always been very helpful and efficient. So it is always team work that gets the job done.

I have made some wonderful friends because of my transplant journey. A group of us celebrate our 10th Transplant Anniversaries this quarter and I hope our stories, together with the achievements of others since transplant, will inspire those of you who are on the waiting list. We were all there once!

Each year DonateLife Victoria has a morning tea to thank their volunteers for their time, support and commitment. This year it was held at Royal Melbourne Zoo. I went along as a DonateLife helper and was also able to represent HLTTV (a DonateLife partner). If you are interested in becoming a DonateLife Volunteer you just need to contact their office.

I was honoured to be made an HLTTV Life Member and look forward to keeping in touch at social events.

Gaylynn Pinniger

From the Immediate Past President

Firstly, after two years as President I would like to thank everyone. It's been awesome and it's time to move on. I would like to congratulate David Hayne as our new President of the HLTTV and wish him well. David brings along with him a wealth of knowledge and experience of which I'm sure the Trust will benefit greatly.

Thank you to Gaylynn Pinniger for her work in the many roles on the Committee over the many years. I would like to thank the dedicated team of people on the Committee at the HLTTV who have worked tirelessly with all the new initiatives, especially Jon Rolfe who kept things running smoothly as well as dealing with unexpected situations.

The festive season is only around the corner and I wish each and every one of you, along with your families, my very best. Keep safe and healthy, may all your dreams come true. Bring on 2013.

Claude Turco

President's Message

At the November AGM of the Trust I had the honour to be elected President of the HLTTV after our immediate past president Claude Turco decided to step down. The Trust under Claude's leadership has gone from strength to strength. Claude has juggled his role as president with the very difficult task of re-entering the work force as he continued to recover from his transplant. I am sure you will join me in extending our sincere thanks to him. I am pleased to say that he is remaining on the Committee where his extensive experience in all matters concerning the Trust will be invaluable.

At the same meeting Gaylynn Pinniger too, who as you will all know has been our efficient and devoted editor of The Circulator for many years, has decided to retire from the committee and as editor of The Circulator and convenor of the twice yearly BBQs. Gaylynn has worked tirelessly over the years for the Trust in so many different roles. She will be greatly missed as editor, convenor and committee member but she has earned and deserved a rest!

The coming year for the Committee and for the Trust is likely to be very busy again with a number of very important issues to be dealt with. The accommodation program for our country and interstate friends, post transplant, has settled in very well (see the separate report in this edition - page 5). A major fundraising effort aimed at financially securing the accommodation program for the long term will target philanthropy outside our immediate transplant family. This effort is deep into the planning stage and we hope it will commence very soon.

Apart from the accommodation program, our work to help all pre and post transplant members and their carers continues. We recently partnered one of our members, Graeme Vessey, dollar for dollar to provide a new and necessary exercise bike for the physiotherapy gymnasium. We are all indebted to Graeme for his generosity and initiative in making possible this bike.

Louisa Walsh our Membership Officer has been busy in a number of areas. As you know the Trust is now on Facebook and Louisa has also opened a Twitter account for us. Please join! She is also in the process of organising a trivia night to coincide with DonateLife Week at the end of February 2013; more about this nearer the time.

By the time you receive this edition we will have had our Christmas BBQ at Fawkner Park. Many of you

will be aware of the controversy when the Melbourne City Council imposed a charge of about \$240 on the Trust for the use of the tiny area of Fawkner Park where our BBQ has been held for many years now. After publicity in the media generated by committee member Jon Prior's father, a great deal of public interest was generated and we received a number of offers of donations from the public and other organisations to pay the fee to the MCC. In the last few days leading up to the BBQ we were contacted by the MCC and informed that the decision to make a charge for use of the parks by organizations such as ours was under review. As part of this review our charge was reduced to \$50.

During the BBQ we were visited by the president of the Mercantile Cricket Club, one of the clubs which has used Fawkner Park for 90 plus years, and he confirmed that his club was still happy to donate to us the full \$240 to cover the original charge. We are extremely grateful for his and his club's generosity. We will keep you informed about further developments in dealing with the city council.

Despite this issue all 120 plus attendees had a wonderful BBQ in beautiful weather. Wendy Moule, who as we all know has been one of the key transplant nurses in the clinic, has announced her retirement. She joined us at the BBQ and so we were all able to warmly extend our gratitude to her and to say farewell. After 19 years in such a busy and important role she has all our good wishes for a long, fulfilling, healthy and happy retirement. A small presentation on behalf of The Trust was made to her.

Finally, as the festive and holiday season approaches may I wish each and every one of you my very best wishes for Christmas and may 2013 bring you all the health and happiness that you wish for.

David Hayne

Special General Meeting

To consider various changes to the Constitution (details page 21)

12 February 2013
7.30 pm
5th Floor Seminar Room
The Alfred

The Committee Meeting will follow the Special General Meeting

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

All welcome

DonateLife Week

24 Feb-3 March 2013

**Make your wish count
discover, decide, discuss
organ and tissue donation.**

HLTTV is planning some exciting activities for DonatLife Week 2013.

One of our activities is pretty 'hush hush' but I can let you know that it's a chance to be creative and promote organ and tissue donation in your own way, and there will be prizes! We'll be releasing details during December via email, Facebook and twitter, so make sure you're connected with us online if you'd like to know details as they come to hand.

The Trust is also aiming to hold a trivia night during DonatLife Week. If you have any prizes or goodies you could donate as small gifts and prizes for the trivia night, we'd love to hear from you. Dates, time and location TBC, but it will be during DonatLife Week, and we hope lots of you will join us for a great social night.

Finally, other organisations, including DonatLife and Transplant Australia, are holding events all over the State during DonatLife Week, including rural and regional areas. If you'd like to be involved in volunteering for a few hours during the week, DonatLife are keen to hear from you. Contact Louisa Walsh, HLTTV Membership Officer

(membershipofficer@hlttv.org.au) for more information.

We're hoping lots of our members can be involved in activities all over the State, to celebrate the gift of life, and promote DonatLife's theme of 'Make your wishes count'.

WINNER OF THE RAFFLE ENJOYS THE PRIZE

John Stephenson, winner of the 1st Prize accommodation package in our major raffle has contacted us to say that they thoroughly enjoyed themselves staying at the Bellevue on the Lakes at Lakes Entrance, the dinner at Lakes Sports and Community Club and the trip to Wyanga Park Winery on the ferry "Corque".

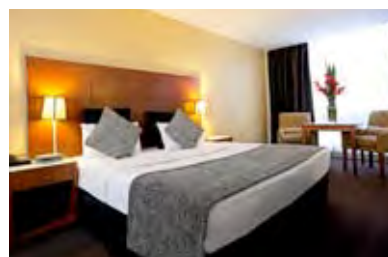
Editor's Note: Please consider supporting our sponsors if you are thinking of a holiday in East Gippsland

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.

With its spacious and stylish studio, one and two bedroom apartments offering modern interiors, comfort and privacy, the hotel provides a relaxing home away from home.



Location: 604 St Kilda Road, Melbourne • Phone: (03) 8530 1800 • Email: 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.

CLINIC NEWS

Wendy Moule Retires

Wendy Moule has decided it is time for her to retire and no wonder as she has so many interests that will keep her busy - golf, body pump, spinning classes, sewing, knitting, reading, theatre, ballet, travel. It may not seem possible but she will probably be even busier than at The Alfred! Then there are her favourite things - cooking and spending time with her family, especially being a grandmother.

Before she left we asked her a couple of questions.

Wendy, when you did your Nurse and ICU training at The Alfred did you think you would be there over 40 years? (Wendy did her Midwifery at the Mercy)

No, I definitely did not think I would still be at The Alfred 40 years later when I did my training here. In fact, I couldn't wait to leave when I finished training and went overseas for two years.

Reflecting on your time at The Alfred's Transplant Clinic, are there any special moments?

My best memories of working in the Transplant Clinic will be the patients I have been privileged to meet with and their extended families. It has been lovely to have that contact for so many years. Another aspect of the job is the wonderful people I have worked with (very dedicated team). Working with such great young people has been a highlight.

Wendy has been a very popular Transplant Clinic Nurse and has been a great supporter of the Heart & Lung Transplant Trust over many years and we will miss her. We send our best wishes for a very enjoyable retirement.

Milestone for Accommodation Program

It is now six months since the Management Committee commenced a program to accommodate patients and their primary carer for the important and compulsory three months after heart/lung transplant at The Alfred. It is now appropriate to report to all members how this program is travelling.

You may recall that the Trust secured the use for 12 months of two, one bedroom apartments at Park Regis Griffin Suites in St Kilda Road with a break clause at six months to assess the feasibility of the program. Park Regis was chosen after lengthy investigations of a number of apartment providers because they offered a very competitive price, they were within walking distance of The Alfred and their standard of accommodation and service was superior.

After six months we are pleased to report that **each apartment has been occupied continuously for the whole period.**

The funding of each apartment is covered by three separate payments. Each State Government makes a payment for accommodation for patients and their carer who live more than 100km away from The Alfred and who need continuing treatment at the hospital. The fee paid by each government varies in amount and all, apart from Tasmania, do not pay a nightly fee whilst the patient is in hospital, although all will pay for the carer for the complete stay. The second tranche of payment to Park Regis is a flat \$15 per night co-payment paid by the occupier of the apartment. The balance, which can vary considerably, is paid by HLTTV through the accommodation program. The good news is that given the support for the program thus far, the break clause has not been exercised and I am pleased to advise that **the program will continue** for at least the next six months.

In addition to the two 'HLTTV' apartments we were able to strike a deal with Park Regis, at a much reduced tariff, to accommodate heart and lung transplant patients from The Alfred who were not able to access our two apartments because they were already occupied. At any stage in the last six months up to four or five apartments, in addition to ours, have been occupied by Alfred transplant patients and their carer.

It is important to say that the Trust **is not subsidising these overflow apartments.** However **the demand for accommodation is over and above what we currently provide** and in order to meet the need we need to raise considerably more funds.

It is most important to understand that **the accommodation program is in addition to and separate from, the usual fundraising and donations** made to The Alfred heart and lung transplant clinics by the Trust. Indeed we have recently provided another exercise bike for the physiotherapy gym in partnership with one of our members, Graeme Vessey. So our work to improve facilities used by all transplants continues. Thus far, money raised specifically for the accommodation program exceeds money spent on the program.

To secure the future of this important program the Management Committee of HLTTV is in the process of planning for the commencement of a major fundraising initiative targeting philanthropists outside our transplant family.

The Committee fully recognises and is committed to ensuring that our normal fundraising activities and donations will continue to be focused on benefitting supporting all pre and post transplant recipients, their carers and all those at The Alfred who make the journey possible.

As we move into a new Committee year we are excited by the challenges that lie ahead and I can report that the Committee is enthusiastic and confident in meeting these challenges.

David Hayne

Skin Cancer Warning

Australia has some of the highest levels of ultraviolet (UV) radiation in the world. Too much UV can cause sunburn, premature ageing, eye damage and skin damage leading to skin cancer.

At least two in every three Australians will develop skin cancer before the age of 70. If you're an Organ Transplant Recipient (OTR) taking immunosuppressants, the likelihood of developing skin cancer is even greater.

In fact, it is estimated that drug-induced immunosuppression increases the risk of squamous-cell carcinoma (SCC), a type of skin cancer, a dramatic 60- to 100-fold.¹

It has also been reported that 40% of all recipients develop pre-malignant or malignant skin tumours within the first 5 years after the transplant. The tumours are generally more aggressive and spread faster. The risk factors for the development of non-melanoma skin cancers (NMSC) include duration and intensity of immunosuppression, age, lighter skin type, and male gender.³

To prevent squamous-cell carcinoma, sun avoidance between 11 AM and 3 PM, application of sunscreen and covering as much skin as possible by protective clothing are highly recommended strategies for transplant recipients.

Heart transplant recipients are particularly prone to the development of these skin cancers.² Vigilant sun protection practices, skin cancer education, regular skin examinations, and daily vitamin D supplementation are important for these high-risk heart transplant patients.²

Almost all skin cancer is caused by over exposure to ultraviolet radiation (UV) from the sun. Sun protection is required when UV levels are at 3 and above, which is the level that can cause skin and eye damage and lead to skin cancer.

For best protection, use a combination of these five sun protection measures:

1. Slip on sun protective work clothing. Cover as much skin as possible. Long pants and shirts with a collar and long sleeves are best.
2. Slop on SPF 30+ sunscreen. It's best to use a broad spectrum, water resistant sunscreen. Apply 20 minutes before going outdoors and re-apply every two hours.
3. Slap on a hat. Wear a broad-brimmed hat that provides as much shade as possible to your face, neck and ears.
4. Seek shade. Take breaks under trees or indoors whenever possible.
5. Slide on some sunglasses. Wear close fitting, wrap around sunglasses that meet the Australian Standard.

These strategies provide the best protection against UV radiation when used in combination.

Early detection of skin cancer is very important as it can often be treated successfully if found early. However if left untreated, skin cancer can be fatal.

All Australians should get to know their skin and check it regularly. Check all of your skin, not just sun-exposed areas. See your doctor if you notice:

- a new spot, lump or unusual freckle
- a mole, sunspot or sore that does not heal

- a spot that looks different from other spots around it
- a spot that has changed colour, size or shape over a few weeks or months
- a spot that has an irregular border or becomes itchy or bleeds.

Visit **sunsmart.com.au** or call the Cancer Council Helpline on 13 11 20 for further information.

References:

- 1 Hofbauer GF, Bouwes Bav-inck JN, Euvrard S. Organ transplantation and skin cancer: basic problems and new perspectives. *Experimental Dermatology* 2010; 19(6): 473-482.
- 2 Brewer JD, Colegio OR, Phillips PK, Roenigk RK, Jacobs MA, Van de Beek D, Dierkhising RA, Kremers WK, McGregor CG, Otley CC. Incidence of and risk factors for skin cancer after heart transplant. *Archives of Dermatology* 2009; 145(12): 1391-1396.
- 3 Ulrich C, Jürgensen JS, Degen A, Hackethal M, Ulrich M, Patel MJ, Eberle J, Terhorst D, Sterry W, Stockfleth E. Prevention of non-melanoma skin cancer in organ transplant patients by regular use of a sunscreen: A 24 months, prospective, case-control study. *British Journal of Dermatology* 2009; 161(s3): 78-84.
- 4 Kuschal C, Thoms K-M, Schubert S, Schäfer A, Boeckmann L, Schön MP, Emmert S. Skin cancer in organ transplant recipients: effects of immunosuppressive medications on DNA repair. *Experimental Dermatology* 2012; 21(1): 2-6.

Heart to Heart Respite House Inc. Report after Annual Meeting



Heart to Heart Respite House Inc. had a busy year in 2012, with the occupancy rate rising all the time. We have just had our annual meeting followed up by a working bee a couple of days later. Most of the trees had grown like mushrooms and we also did quite a few jobs to make life easier for us all, you will see the difference.

The House has proved itself to all who have stayed there, and to read the comments book is very pleasing. All want to return, with the Mighty Murray River just a block away

(perfect for fishing and swimming) and the Barmah Forest right on your door step, ideal for bush walks.

Heart to Heart does not receive any Government grants, so the committee are always on the lookout to generate extra money to keep the house in great condition. All the funds are raised by the committee to operate the house, plus donations.

Our records show that 99% of patients, carers and families are the ideal occupants, however when

four people stay for six nights and donate \$12.50 per head and another couple paid half of their \$10.00 linen hire, and no donation at all, then the committee and members at the annual meeting decided to have a minimum amount per night stay.

It is regrettable that it had to come to this, but I think you will find the minimum amount very acceptable. In the future adults pay a minimum of \$10.00 per night and children are free. Linen hire (or bring your own) of \$5.00 per head per stay up to six nights stays the same.

The Committee and members of Heart to Heart Respite House Inc. wish you all a Very Merry Christmas and Prosperous New Year, and we hope to meet you in the near future.

Bill Vickers
President

Bookings & Information

Martina Appelman
Mobile 0409 957 492

Laraine Anderson
Tel 03 9770 7197
Mobile 0418 599 745



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 or tel **03 9531 2234**.

TRANSPLANT ANNIVERSARIES WE WISH YOU MANY MORE

October

Lung/s: Bill Carkett 2002, Trevor Davidson 2009, Kaye Hayne 2006, Janet Johnson 2011, Valerie Ann Shentzer 2011

Heart: John Campbell 2008, Phillip Felman 2005, Robin Oliver 2000, Jeffrey Priest 2008, John Russo 1992, Peter Triffet 2003, Libero Viola 1992

Heart and Lungs: Claire Stubber 1996

November

Lung/s: David Biram 2010, Phillip Buckland 2009, Ian Casey 2008, Len Hain 2002, Carol Ann Hoare 2009, Jason King 2011, Andrew Kirby 2009, Nicola Radocaj 2002

Heart: Paul Allen 2011, Jennifer Ball 2009, Lyn Budge 1986, Janice D'Aprile 2006, Fulvio Filipponi 1993, Bernice Hallam 1996, Adrian Sayers 2007, John Turley 2002

December

Lung/s: Kenneth Catlow 1997, Wendy Jenkins 2006, Graham Mitchell 2011, Alison Walters 2004, Peter Wanko 2009

Heart: David Ash 2008, John Bisiach 2002, Ena Clark 1999, Greg Dartnell 2004, Eric Gill 2009, David Hales 1998, John Jones 1989, Dennis McCarthy 2008, Gaylynn Pinniger 2002, Russell Wills 1991

Congratulations to Libero Viola who celebrated his 20th Anniversary



10th Anniversaries

Bill Carkett

(William Carkett - 'Willy Carkit' was the joke. Bill says he hasn't lived up to his nickname and this is why)

Reached my 10 years anniversary left lung transplant in October. Thanks to my wife Rose and the bestest and nicest people at The Alfred Transplant Clinic. Also all the other Departments in The Alfred that have looked after me.

First thing my family did once we got the OK was book a holiday to

Fiji and it was fantastic. I never thought I'd be doing this again. I taught my granddaughters to snorkel - funny feeling breathing through a snorkel, not an oxygen mask. Had many lovely walks along the beach - even chased the grand kids.

Back at home I keep up an exercise routine which includes the gym doing cardio and weights (not to body build - just keep fit), swimming and having a walk most days which over time the distance has increased. Also gardening and home maintenance - all these activities that were impossible a few years before my transplant.

Since our first trip to Fiji my wife and I have had another holiday in Fiji, travelled to Thailand twice, the USA, New Zealand and Vanuatu. We have travelled around Aussie - WA, Queensland a few times. Drove to Sydney up the Hume Highway and back down the coast to home. We have mini holidays at Victorian places during the week when it's cheaper.

Len Hain



Len enjoys celebrating his transplant anniversary each year with family and friends (including transplant friends) and often these events are long and jolly affairs. This anniversary found Len in Cabrini Rehab following a hip replacement operation at The Alfred. On the actual day Len was accompanied home by an Occupational Therapist to make sure everything was ready for his return, and was back in time for lunch. Len was given a small 'surprise party' by his wife and transplant friends to celebrate his 10th Anniversary but had to be content with a hospital meal.



his wife Maria have made two trips to Croatia to visit his elderly mother, brother and three sisters. The second trip this year was for three months and they thoroughly enjoyed the experience of travelling all around Croatia.

John Turley



walks - but always finds time for socialising! Enjoys helping out her elderly father so that he can stay in his home. A little travel. Darwin twice, one of those trips on the Ghan Railway which was wonderful. Interstate trips to New South Wales and South Australia for special events have been enjoyed, as well as two trips to Auckland to visit a friend.

John Bisiach



Would Len make it to the Christmas BBQ which he never misses - that was the big question at the time. Well he did make it!

Len knew it was time to face the hip operation when he could no longer manage to go and watch his beloved Collingwood Football Club play at the MCG. Perhaps he'll now be ready to train with them!!

Len has continued to run his real estate business all through his transplant journey and even when in hospital this time. Len enjoys life to the full.

Nicola Radocaj

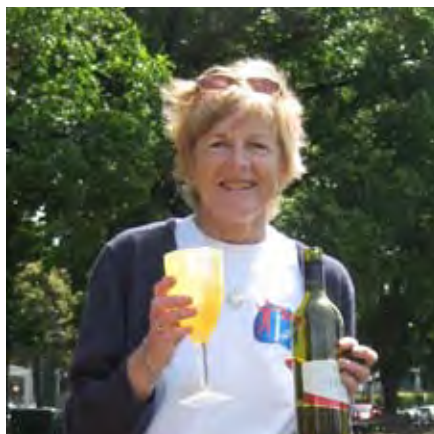


Nick has kept himself very busy with renovating and gardening and helping his family. Since his transplant Nick has become a grandfather and he and

John has been fit and healthy since his transplant. John, his brother and some friends meet up each day for an hour's walk at the various beaches along the coast not far from where he lives in the Geelong area. The walk is followed up with coffee at a nice cafe.

John and his wife Norma have done a lot of travelling with friends in Australia and most of all they have enormous enjoyment having three grandchildren aged 8, 6 and 3.

Gaylynn Pinniger



Time to celebrate. Life seems hectic even in retirement. Regularly attends the gym and tai chi classes but never seems to find time to go for those

At beginning of November 2002 John went off to work in Darwin as usual. Little did he and his family know of the journey that was to come. After a sudden heart attack John was flown from Darwin Hospital to Melbourne on a normal Qantas flight as an emergency patient. He was extremely ill and spent almost eight weeks in The Alfred ICU before his heart transplant. As soon as John had finished his rehab and recovery he and his wife drove back to Darwin. Enjoying his 'second' life he completely renovated his house and spent time fishing and crabbing the Top End in his tinny.

Finding that both sons had moved to Melbourne, John and his wife Sue made the move here despite the colder weather. John was kept busy on arrival when he joined the Heart & Lung Transplant Trust and is a past President and Life Member. When John's wife Sue retires they intend to travel to Europe for a longer period than the short holidays they now enjoy. In the meantime John is kept busy baking bread, cooking, renovations (once again) and as a HLTTV Patient Support contact.

ALPHA ONE – MY JOURNEY

Steve Wright

In September 2008 my wife, Jane, and I drove up to Noosa Heads (our favourite holiday destination) for a two week holiday. It was our first holiday without kids and we were looking forward to a two week break of just being together. When we arrived we went to visit good friends Linda and Ivo for a BBQ at their property at Mt Tinbeerwah.

After driving 24 hours to get there we did not look our best and I probably did not look all that healthy. At this point Linda said that I did not look well and decided that I should see a doctor for a check. She recommended her doctor out at Cooroy. We, Linda, Jane and myself, travelled together to see the doctor. He was a young doctor with earrings and long hair in a ponytail, not the usual stereotype. He examined me and referred me for full blood tests and a chest x-ray. He called a couple of days later and asked us to come in again to see him. When you get a call like that you know something is probably not quite right.

The three of us went in again and were given the news that I had a rarely diagnosed condition called Alpha 1 Antitrypsin deficiency (A1AT). It is the lack of an enzyme that protects the liver and/or lung from damage. It had caused serious lung damage known as either emphysema or COPD. It explained many things – why I was prone to childhood bronchitis, a life of asthma and, more recently, severe shortness of breath. It was a genetic condition also possibly affecting my siblings and children. All family members were checked with my older sister discovering she also has the deficiency. She is in reasonable health but struggles somewhat with breathlessness when, for example, she walks up hills.

Since the early nineties I had always struggled with exercise, particularly surfing which was (and remains) a passion. I had not surfed since the early nineties as the exertion was too much. Since the late nineties I was also prone to periodic “asthma attacks” which would take up to 15 minutes to get over. These were quite acute and scary. Going for walks I always had to stop to catch my breath to the point where I could not walk any great distance without a serious struggle.

The condition was worsening over time but my body made some allowances for it. I lost up to 8 kg (down to 62 kg) and my oxygen levels were quite low – down to 91% saturation level however I was still able to get around and do many of the “normal things” of life. From early 2009 however I became more and more short of breath and was referred to a thoracic specialist. He had some experience with A1AT and referred me to a six week, two day per week, pulmonary rehabilitation program with the local Community Health service. It was apparent during that program that I was well below average in lung performance and although it was of some benefit my condition kept deteriorating.

In July of 2009 it was recommended that I go on to oxygen therapy 16/24 hours daily at 2 litres per minute. I was provided, free of charge, with an oxygen concentrator at home and portable oxygen bottles for going out. After about six months and no improvement, the oxygen was increased to 24 hours daily. It was difficult to do anything but sit or lie down. To walk more than 10 metres was a serious struggle. It affected me in many ways – from showering (30 second showers with oxygen at 4 lt/min and 15 minutes recovery time)

to the ability to go to work. My work has been fantastic in the support it gave me, allowing me to work from home which I have continued without a break – it has been excellent therapy. Thank goodness for email and the Internet. The condition was worsening, making many tasks impossible – going shopping, doing any sort of housework inside or out, visiting, going out for dinner, basically anything that involved any exertion whatsoever. To go in the car meant getting to the side door of the house where the car was parked 3 metres away, resting for 5 minutes, ensuring the oxygen in the car was on and as quickly as possible getting to the car and getting the nasal prongs on. If there was any delay I would go into a state of anxiety and have, what I would term, a severe asthma attack. I was prescribed medication to help with the anxiety, which I became dependent on. If I had to do anything that involved physical exertion I would take one – it gave me some respite and a little improvement in breathing. Overall quality of life had slipped to a very low ebb – not just for me but everyone around me. It felt as though everything was falling apart – physically and mentally.

I was not getting any better and was subsequently referred to a second pulmonary rehabilitation program with the Community Health service in January 2011. My condition had declined significantly from the first program. This was demonstrated by a key indicator – the six minute walk test. In mid 2009 I completed about 300 metres in the six minutes with oxygen levels reducing to about 87% - not good! In early 2011 I completed 157 metres with several stops and oxygen levels reducing to 79% - really, really not good! With some trepidation and delay, I was then referred to The

Alfred to assess options. They were to undergo surgery either to remove some of the damaged lungs (a lobectomy) or full double replacement (a transplant). Both options scared me to death. However, as the consulting surgeon stated, I only had until the end of the year to live. This made the option of surgery a “no brainer”.

I was initially looking at the less dramatic lung reduction option until I went through lung performance testing. The result was that lung reduction would only delay the inevitable for a short period and that replacement was really my only option. The surgeon made it very clear I would also probably not survive the reduction surgery as there was not much there to keep me going. I will never forget the surgeon drawing a graph – a descending line with death at its end – and showing me where I was on that graph – near the bottom. Both Jane and I went numb (and emotional) realising I was pretty much gravely ill and a serious decision had to be made and made quickly. Again it was relatively easy – lung replacement was the only option so let’s do it.

At that point I was booked in for the in-patient assessment for transplant. In late May I had the standard three day stay in hospital to test suitability for surgery. If I failed then that was it – about eight months to live. I had to be transported by wheelchair to all the tests across the hospital as walking was too difficult. Thankfully I passed all the tests and received a call a week later to say I was now on the list. I had to go in and have blood samples taken to go to all major hospitals across Australia for possible lung matching. I had more testing to go that was routine but the most important thing I was now on the activated waiting list.

In late May I had two more tests – a dental assessment and an angiogram. They were not easy – I had to have three teeth removed (or root canal fillings) then and there due to potential infection - two at the front and one molar. (I am now an official Collingwood cheer squad

ambassador). The angiogram, via the wrist, detected an 80% blockage in the right hand coronary artery which was immediately addressed by a stent being inserted – I was so lucky as this was a potentially life threatening condition only detected because of the standard transplant assessment testing. The insertion of the stent resulted in the need for me to go on a course of blood thinning for 28 days to ensure it was successful. Unfortunately it meant that I was taken off the transplant list albeit temporarily for that period. I felt ok and was happy to delay any surgery for the time being - although it was getting close to a point where I may become too sick for the operation and that, again, would be curtains for me.

For the next 18 days of the 28 day blood thinning process I waited knowing I would be back on the list after the 28 days had expired. It was then July 14 and my younger daughter’s 20th birthday. We had a small family get-together that night with a planned dinner out over the next night or so. We went to bed as usual after cake and candles. Early the next morning was the telephone call that changed my life. At 4.15 am on July 15 the phone rang. Usually when the phone rang at that sort of hour it would be Ozchild asking if we can take an emergency foster baby (as we are foster carers with them). Both Jane and I picked up a portable phone each and answered it. On the other end was an unmistakable Canadian accent. We both knew who it was. It was Nicole from the transplant unit at the Alfred. She said “we have just received a wonderful set of lungs for Stephen – you need to come up straight away”. Jane asked if this was it – “was the transplant on?” The response was “you bet – just get here was soon as you can”.

I did not, in fact, could not say a word. I had gone from being asleep to a state of total anxiety/panic in less than 10 seconds. I knew it was Nicole and I knew why she had rung. My breathing was labouring, the oxygen was turned up full and I started shaking.

I remember saying to Jane “I don’t know that I can do this” She was very reassuring but I did not have any other thought but to breathe. The oxygen did not seem to help. I was just gasping. I decided to have two anti-anxiety tablets (4 times the usual dose) – they did nothing. I could not move. I could not get dressed. I was meant to shower but that was way beyond me. I sat for about 90 minutes just trying to breathe and cope. I remember putting one sock on and taking 15 minutes to do that – eventually the other sock went on. I could not get dressed any further so I put on a jacket that was next to the bed and that was it. Still in pyjamas, time was getting on and we must go.

It took every ounce of effort that I had to get myself into the car and onto the oxygen bottle that Jane had already turned on to full. I was still severely breathless and could not stop shaking. She drove up to the Alfred, an hour and a half away, arriving at about 7am. On the way I was able to phone our five children and my oldest brother and let them know what was happening. Just before arriving at the hospital we had another call from the Alfred wondering where we were and informing us that time was pressing as the donor was also donating a liver and that had to get to another hospital urgently. We were only a couple of minutes away but the urgency of the call sent me into another anxiety attack.

We arrived at the Emergency Department of the Alfred to be greeted by Nicole, the social worker Jane and other nursing staff. I was in a state of panic until Jane, the social worker grabbed my arm and said “Steve – you’ll be fine, we don’t lose anyone in this operation” With that, I tried to resign myself to just letting the medical team do their thing and for me to stop panicking. I was admitted, weighed, x-rayed, and given medication intravenously. From that point I do not remember anything except a flash of being moved to the operating theatre. The next thing I remember is waking up the next day with family

around me, no oxygen prongs and a vague sensation of a breathing tube being removed from my throat. New lungs!! Such a precious gift from an unknown donor.

Footnote – Some notes of thanks.... I have the most wonderful family and particularly Jane who has supported me all the way. I could not have done it without her. She has been so caring and loving. She pushed hard for the medicos to act quickly as she knew how sick I really was. All of our children also have gone through a very difficult time not knowing what the future would bring. I also convey a big thank you to my brothers Patrick and Tony and my sister Ro who have been with us throughout the journey and particularly at the critical times in hospital.

In addition, of course, I would not be here without the expert team at the Alfred hospital. What can I say – they have been fantastic; so professional, thorough and caring. From the initial meetings with Prof. Glen Westall, Mr Julian Gooi and Jane Harris, to the assessment process at the Alfred Centre with Nicole Gauthier, the transplant co-ordinator, to the actual surgery performed by Mr Michael Rowland (whom I have never met) to the Intensive Care Unit and to the team on 5 East ward there are so many people involved – ward staff, nurses, doctors, surgeons and the different teams – Air One, Cardio-thoracic, Physio, OT, Nutrition, Pharmacy, Xray -the list keeps going. I estimate more than 100 Alfred staff have been involved to get me to where I am now. To them all, I can't thank you enough.

I have one final thank you that is the most difficult – to the donor and family. What a gift! I hope the family gained some solace from the knowledge that their loved one has given new life to a number of recipients including me.

Footnote - About three months after being diagnosed we had a phone call from our dear friend Linda to see

how I was. She said she had been complaining of a chest pain but the doctors could not tell her what was wrong. A few weeks later she rang again and without any emotion said "I've got cancer" It was actually asbestosis or mesothelioma. She died about 12 months later.

Further footnote – it is now 14 months since my transplant and I have gained 25 kg (I need to stop eating!) and attend gym three days a week. I feel wonderful and wake up every morning so grateful to all concerned and think how lucky I am. There have been some minor issues but life is so good and I have been given such a gift.

Steve

New Book Release

MORE THAN A FOOTNOTE: The Story of Organ Transplantation in Australia and New Zealand
Edited by Brian Tait PhD

The book recounts the history and development of organ transplantation in Australia and New Zealand with first hand accounts from surgeons, physicians, scientists and transplant coordinators. It details a half-century of clinical transplantation.

It is not only a clinical history, but also a forum for the patients and the donors who provided them with the ultimate gift, the Gift of Life.

Available from *Australian Scholarly Publishing.*

AROUND THE BAY PARTICIPANT JOHN OULTON REPAYS THE COMMUNITY

John Oulton's eldest daughter Imogen received a double lung transplant as a 9 year old in 2007. Imogen is doing well and leads a pretty normal life.

To support The Smith Family's Charity which helps disadvantaged children and young people to get the most out of their education, John completed the BUPA Around the Bay bicycle ride - 210 km around Port Phillip Bay on Sunday 21 October 2012.

John has also participated in other charity rides since 2007 and has helped raise more than \$1 million for the Ronald McDonald House at the John Hunter Hospital in Newcastle and Tamworth. He said it was his way of giving back to the community as they had lived at Ronald McDonald house in Melbourne for about three months when they had to come to Melbourne from their home in Brisbane at the time of Imogen's illness. They now live at Avoca Beach in New South Wales.



John and his wife Jacqui, post ride

SELF CARE DAY FOR VAD PATIENTS AND CARERS

Waiting for long periods for a transplant can take a toll on patients and their families. Social Worker Gillian Coult felt that some self care treatment might be good and organised a half day session on 29 October in the Boardroom, West Block at The Alfred. Two lovely Body Shop staff came along as part of their corporate responsibility program to do makeovers and hand massages. Two Alfred Volunteers who offer hand massages to patients were also available. Looking for something more appropriate for the men, Gillian thought of engaging a masseur but funding would be needed. She approached HLTTV to assist. Other activities were available and everyone had a great time catching up in a relaxed atmosphere.



Shiatsu Massage Practioners



VAD Co-ordinator Rebecca Stornebrink tries out the service

GETTING TOGETHER OVER LUNCH

A group of around 20 got together for an enjoyable time on Sunday 14 October 2012 at the Matthew Flinders Hotel in Chadstone, Vic. Committee Members welcomed pre and post transplant patients and carers.

VALE

Willi Deyssing

Willi passed away peacefully on 24 October at The Alfred. Our thoughts are with his wife Helen, daughter Liann and son Ulrick.

Willi had his transplant just over 5 years ago, after several years of battling with frequent bouts of heart failure caused by Cardiomyopathy, probably because of a chance viral infection. After a slow recovery and a couple of periods of rejection, life started to look up and he happily attended his regular rehab classes (alias “torture sessions”) first at The Alfred and then at Caulfield. Being now the proud possessor of two hearts, he enjoyed stating that he was now related to Dr Who (he even commissioned a giant scarf from his daughter to prove it) and took a certain fiendish delight in watching the faces of unknowing health care workers before they understood why his pulse rate was so rapid and irregular.

He was soon able to do many of the things that were important to him such as maintenance jobs around the house and on family cars, being a HLLTV committee member and cooking delicious meals for family and visitors. He was also able to enjoy lots of happy times (such as playing Santa at the Christmas BBQs) with family and friends and was able to travel twice to Germany to visit his ailing Mother and other relatives. As a proud Bavarian he especially enjoyed a very merry evening at the Munich Oktoberfest.

Unfortunately, the last 18 months saw problems with depression, side-effects of drugs and loss of appetite slowly erode his sense of self and well-being and his increasing frustration and his determination to not be a burden on his family or society finally pushed him to follow his belief that “quality of life is more important than quantity” and to ask to go onto palliative care.

He and his family were/are ever grateful for the extra years that his transplant gave them together and for the boundless care and support provided by the staff at The Alfred throughout the whole amazing journey.

Into every life a little rain must fall and then the sun comes out again

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.hlltv.org.au/> and follow the 'Membership' links to pay online.

CHRISTMAS BBQ A GREAT SUCCESS

Fawkner Park, Sunday 25 November 2012 - What a day! What a great crowd! Lots of first timers, including Henry who had come along after 16 years post transplant. Great that Adam could come across from the hospital to join in. Coen also come across from the hospital where he has just had his double lung transplant. The Ashton family can now look forward to eventually heading home to Queensland.

When Jeff Campbell came along to his first HLTTV meeting in October little did he know he would go away being our new BBQ Co-ordinator. Jeff took on this role with gusto and thanks to his efforts most of the BBQ supplies were donated by **Foodworks Head Office Glen Iris**, and vouchers to the value of \$280 were donated by **Coles Rowville**. These came in handy for buying other items.

And to top it off Jeff was at a K Mart Store when he was approached to go in a free raffle, the prize being a BBQ. Although in a hurry Jeff waited as there weren't many there and he thought he might have a reasonable chance of being the winner. When the time came there were about 200 people but he still managed to be the lucky winner. In fact, we are the winners - Jeff has donated the BBQ to HLTTV.

Thanks to **Kennards Hire** Richmond Branch for supplying the folding tables and gas bottles and the **O'Kelly Group** for donating the plastic plates, knives and forks, and paper serviettes. Thank you also to **Moo Meats** which kindly offered to again donate meat if it was needed for the Christmas BBQ.

Jeff did a superb job as Co-ordinator with help from his wife Elly and son Brendan. The Prior family once again did a great job with the cooking. Martina and Rom were kept busy selling the raffle tickets and the raffle was a great success. With lots of winners to be drawn David and Jon had to just keep rolling that barrel! Thank you to Kelina Attard who came along to help. It was also a wonderful opportunity to be able to personally say farewell to Wendy Moule on her retirement.

Finally, a special thank you to everyone who came along and supported the Christmas BBQ.

The next BBQ will be the Easter one - as usual on the Sunday before Easter (24 March 2013)

Below left: A bit hard to bring your own seats when flying over from Tassie

Centre: Peter catches up with Flick on his trip down from Townsville

Right: BBQ Co-ordinator Jeff finally gets a rest



Coen Ashton

The pre and post transplant group

REFLECTIONS FROM THE TRANSPLANT GAMES IN NEWCASTLE

by *Flick Nolan*

I have just returned from my 9th trip to the National Games, two as a recipient wife, and the last seven as a donor wife. It is always good to see old friends and it is always sad to find out that someone has passed away. You always meet new people and hear about their journey, so the time is often filled with mixed emotions as new donor families and young children always have a big story to tell.

The Opening Ceremony was held at Customs House Plaza and was very well attended. Derryn Hinch was the MC and there were speeches by Ministers of Health and other official guests. Then the donor and living donor families came to the front and released 50 monarch butterflies. The butterfly release assists in replenishing the depleting butterfly population and in this Donor Family Tribute, provides a beautiful symbol of the life and freedom donors have generously given to transplant recipients.

I was extremely honoured to be asked by the CEO Chris Thomas to read a poem at the Opening Ceremony when the donor families took a huge wreath of flowers, that said THANK YOU, down to the surf boat at Nobby's Beach. The lifesavers rowed with the wreath out to sea and when they lifted their oars upwards to the heavens, I was to read the poem My Final Gift as they put the wreath overboard. Wow that was an amazingly emotional time for all.

My Final Gift

It is now time for me to move on
Into the dusk, but also the dawn.
I will remain as the morning comes
As I've left behind a gift for someone
So another may walk, may talk, may see
Where their life was locked, I offered a key
I am a donor to someone in need
My final gift, my final deed.

There was a fitting reception afterwards for the official guests and donor families and the Donor Family Quilt was on display there. Behind every recipient's success story is another story of an Australian family who made it possible by donating their loved one's organs. Transplant Australia is proud to continue to support the Australian Donor Family Quilt – dedicated to keeping the memory of these wonderful people alive. Donor families from across Australia have prepared a personal tribute to their loved ones and these have been lovingly sewn together to form a unique tribute to their generosity. Behind every 'patch' is a story of someone who lived life to the full and was prepared to give life by becoming an organ and tissue donor. The Australian Donor Family Quilt will be an ever-growing commemorative piece dedicated to donors.

There were many sports played over the next week, and I helped in the water with the children as that is what I do as a job. One little chap (4) was starting to sink a little so I put my hand under his tummy and started to talk to him. He immediately hung on to my hand and swam with only one arm! I told him that I would not let go to reassure him as he really needed to be seen swimming with two, but it didn't matter as he was coming last and he didn't want to let go. The crowd was amazing with their cheering – very hard not to have a tear with those things!!!

Jack had always been a sportsman, playing league football and afterwards many other sports, so it was a huge shock when he very suddenly became ill with cardiomyopathy and was told three weeks later that he needed a heart transplant. We had to wait 13 months for his gift and afterwards his life became normal again and he was able to rekindle his love of sport representing Victoria and then Australia in National and World Games. His comment when he saw youngsters racing for the first time was "Hey that's not fair, I've had a life these kids haven't".

That comment and my work with special needs children stayed with me and our family and Transplant Australia decided that we would like to donate a trophy in his honour for a youngster who has had a tough road and may not win anything, but has the right spirit.

We had five years more with Jack than we would have had it not been for his 17 year old donor who was a triathlete, and after his cycling accident donated to seven people. Unfortunately Jack died as suddenly as he became sick, but on the roadside, and we were able to donate his corneas and tissue, as organs were out of the question due to the drugs he was on. A young woman can now see her husband and three children, and his tissue went to some of the Bali bomb victims.

I gave the Jack Nolan Memorial Trophy at the closing ceremony as an encouragement award to a young girl who had her first liver transplant at 2, second one at 6, third one at 10, and last year she received a kidney from her mother – and she's only 13 !! We think we have problems!

Everyone has their own reasons for becoming a donor, and it is important that your family, partner and friends understand those reasons, so that if they are ever faced with having to make the decision about you, they immediately know your wishes. Recording your decision on the Australian Organ Donor Register is voluntary and you have complete choice over which organs and/or tissue you wish to donate. You must be 16 years or older to register. The Donor Register lets authorised medical staff who have permission from the Australian Government, check your donation decision anywhere in Australia, 24 hours a day, seven days a week. They can then give that information to your family if needed. Your family will always be asked to confirm your wishes before donation can go ahead, so remember to discuss your decision with your family and those close to you. Visit www.donatelife.gov.au/decide

DISCOVER, DECIDE, DONATE

DON'T TAKE YOUR ORGANS TO HEAVEN, HEAVEN KNOWS WE NEED THEM HERE

I have come away from these games being very privileged to have been able to be on both sides of organ donation.

Flick

13th Australian Transplant Games Participant Louisa Walsh



During my transplant assessment, the physiotherapist asked me to name three post-transplant goals. At that time I was so breathless that I couldn't walk from one end of the house to the other. I can't remember what my other two goals were, but my last goal was to compete in the transplant games. Just over two years later I got that opportunity, at the Australian Transplant Games in Newcastle.

The Australian Transplant Games are held every two years. In the 'off' year, the World Transplant Games are held. The games give the opportunity for transplant recipients from all over Australia and New Zealand to compete in a range of sports – from Scrabble, to Petanque, from Volleyball to Track and Field – there is something for everyone. It's a great chance to meet other transplant recipients, have a fun (and fit!) time, and promote organ and tissue donation.

There are also events for supporters, donor families, and living donors.

I headed up to Newcastle by myself and met a lot of people from all over Australia. It was also great to meet some past and current HLTV members, and also lots of people who have had their transplants for more than 10 years. It was very motivating and inspiring for someone who is still in the (hopefully!) 'early days' of their transplant journey.

In terms of competing, I took the view that I would just have a go at everything (I'm not a spectator!) - so I competed in volleyball, track and field, swimming, the fun run, netball and badminton. I ended up with a medal for every event I went in – 15 medals in total! My biggest surprises were a gold in shot put (and anyone who has seen my skinny arms would be amazed) and a silver in the 3km run.

I would encourage all our members to think about giving the transplant games a go. You don't have to be a fitness freak – it's all just about participation and there are events to suit everyone. It's a great social time and a chance to meet people who have gone through a similar experience to you. The next Australian Games will be announced shortly, and if you can't wait that long then the World Games are in South Africa next year!

Louisa

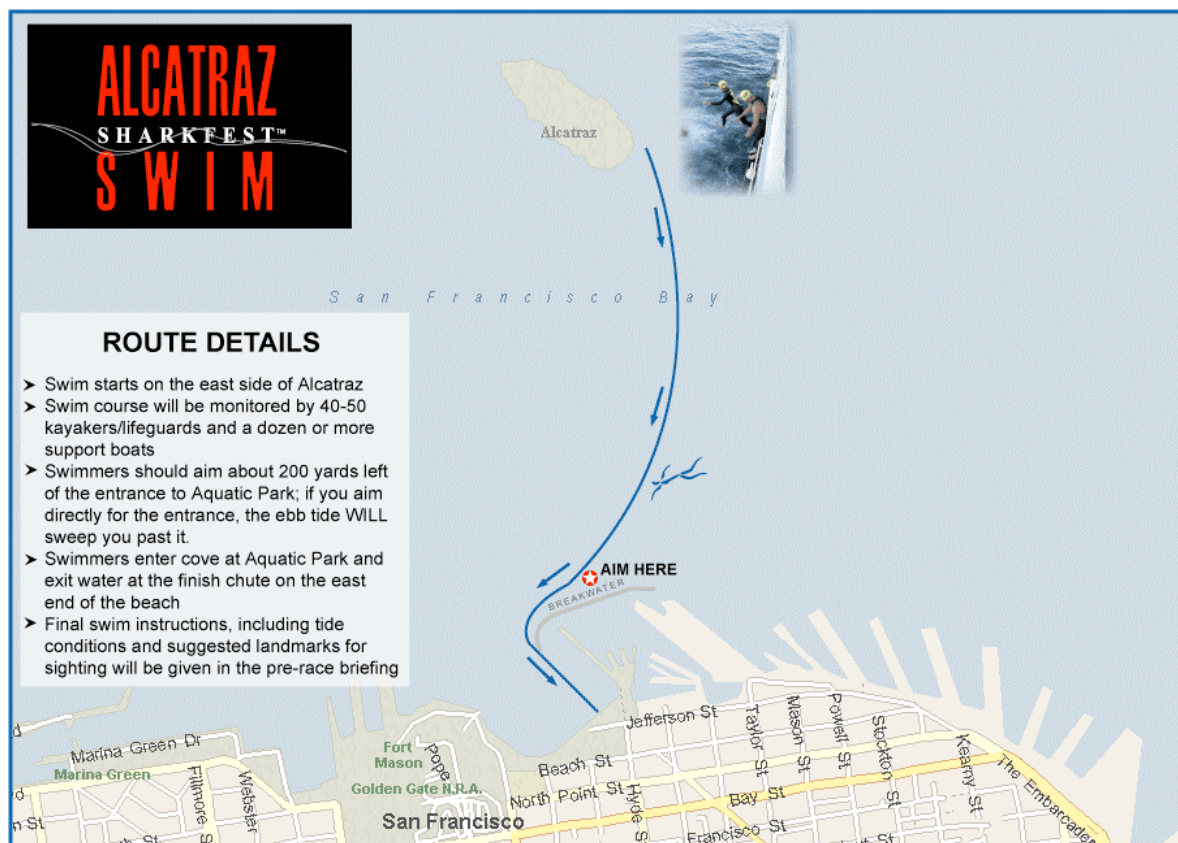
Congratulations to our other members who participated and won medals - Lyn Budge, Nancy Reynolds and Ray Gogoll.

I Escaped from Alcatraz!

Alcatraz Island is located in the San Francisco Bay, 2.4km offshore from San Francisco, California, USA. Often referred to as “The Rock”, the small island was developed with facilities for a lighthouse, a military

mates: Paul, the South African who lives in Melbourne; and Derek, the Englishman who lives in the UK. Jane, my wife, and Isabelle, my daughter, will be staying home this trip as Isabelle will be having her

competing in the Open Water swims around the Melbourne bay over the Summer – Lorne Pier to Pub (1.2km), Portsea (1.5km), Mount Martha (1.2km), Port to Park (1.2km), Half Moon Bay



- ROUTE DETAILS**
- Swim starts on the east side of Alcatraz
 - Swim course will be monitored by 40-50 kayakers/lifeguards and a dozen or more support boats
 - Swimmers should aim about 200 yards left of the entrance to Aquatic Park; if you aim directly for the entrance, the ebb tide WILL sweep you past it.
 - Swimmers enter cove at Aquatic Park and exit water at the finish chute on the east end of the beach
 - Final swim instructions, including tide conditions and suggested landmarks for sighting will be given in the pre-race briefing

fortification and a military prison. It was a federal prison from 1933 until 1963. Alcatraz was notorious as being “escape proof” due to the cold water, strong currents and sharks in the waters surrounding the island. One reputed successful attempt was made by the Anglin Brothers and Frank Lee Morris on the night of June 12, 1962, they were never found.

My challenge, along with 800 other participants, was to complete the swim from Alcatraz back to the San Francisco shore on 29 July 2012. I was joined in this madness by 2

scheduled chicken pox vaccination and because of my immunocompromised status, I have been advised to stay away. This will be a “boys only” trip!

I discussed my plan with Matty, my general coach from Trifitness, and Johnny van Wisse, the swim coach (3 times Round Manhattan Swim winner). They are both full of confidence that I can do this, I am not so sure. Training started in earnest in December last year. At this stage I am trying to complete 3 training swims in a week plus other fitness activities. I am also

(3km) and Bonbeach (1.2km).

As Autumn sets in, getting up at 5.30am for swim training is beginning to take its toll. It is cold and dark, but at least the pool seems warm by comparison. I realize that 15degC is the projected temperature of San Francisco bay so I need to do some cold water training, the pool temperature of 27degC is no good for that. I persuade Paul that we need to get in the Melbourne bay at 10degC for a few weekends.

The first practice swim off Elwood beach is horrific. I waded in the

water and immediately can't breathe, it is so cold. My exposed hands and feet are beginning to go numb. I can't even begin to swim. After 5 minutes of treading water I start to feel acclimatized and begin to swim a few strokes. It is hard to breathe and swim when every time you put your head in the water it freezes. Paul is complaining bitterly next to me, cursing and swearing as to why we are doing this! After 10 minutes though, everything begins to feel a little easier and we begin to swim properly and get into our swimming rhythm. We train again in the cold for the next few weekends and those first 10 minutes don't get any easier.

The flight day arrives soon enough and I am on the plane to San Francisco via Auckland. It is a long flight, but fortunately I am able to get some sleep and before I know it, landing in San Francisco. I head to the hotel to check in and find out where Derek is. Paul is arriving later that day. Derek is having a few beers in a "dodgy" San Francisco bar, typical Derek approach to training!

We have dinner and it is early to bed for me, the travel and jetlag is pretty exhausting. Next day I persuade the boys to get in the bay for a practice swim. We head down to Aquatic Park, which is where the finish of the swim will be, just by Fisherman's Wharf. We hit the water and it feels so warm by comparison with the bay in Melbourne! Conditions are great and it feels good to stretch out after the long flight and swim off the jetlag. At this point, we all get a sense of where each other is at with regard to swim standard. Paul is far and away the strongest swimmer of us all. I am next strongest but Derek is worryingly far behind. Paul and I are wondering if Derek will finish.

It is an early start the next day, a quick breakfast to fuel us up at 5.30am and we are registering at the start at 6.15am. The officials tell me I am the first transplant person ever to attempt the swim. We pick up the official race cap & timing chip and our hands are marked with race numbers, the nerves begin – this is real!

We all trudge down to the ferry terminal through the quiet San Francisco streets on a Saturday morning looking like we were attending a party for wetsuit fetishes! There is nervousness in the air as we board the two ferries for the trip across to the island. The swim organizers are not allowed to disembark us on the island as it is a national park, so we will have to jump directly into the bay from the ferry. The drop-off point is behind the island, so you actually have quite a swim around the island to the start line. Derek is moaning that nobody told him he has to swim to the start, while Paul is attempting to chat up a couple of ladies from Austin, Texas.

After the short trip, the moment of truth had arrived as the sirens sounded for a mass jump off the boat into the cold water. 800 people descend into the bay over the space of a few minutes, like a colony of penguins jumping off the ice floe. On the ferry trip over I had a good look at the water conditions and, aside from the mid-strait chop and swell, it was all pretty calm with very small chop and little wind. I couldn't have asked for better conditions.

I hang onto the goggles on my face as I am told that sometimes these get ripped off of your head by the water as you jump in. The coldness hits me immediately, but it is so much warmer than the bay in Melbourne – thank goodness for my training! I gather my thoughts and swim off to the start line.

I am about halfway to the start line and I hear the siren sound for the official start – oh dear, I am not even at the start line yet! I start my watch and get down to the serious business of stroking out and getting into my swim rhythm. It is too far off to sight properly from the city so I end up following the line of a safety kayak which is about 100m in front of me.

I am gradually getting closer and closer to the kayak over the next 30 minutes or so and finally I am close enough to see the Aquatic



Presentation of medal and wine

Park breakwater exit point out of the bay current. At this point I am actually enjoying the swim. I breathe to my left to look at the Bay Bridge, I breathe to my right to look at the Golden Gate Bridge and directly in front of me is downtown San Francisco – how amazing! By this stage there is a bit of a swell and coldness as I cross the mid-strait current, but it is quite manageable.

Very soon I am close to the breakwater and I realize that I am actually going to finish this, only a few hundred metres more to swim. I have followed the right course to avoid being swept by the current past the finish and out to the ocean under the Golden Gate Bridge, just the Aquatic Park to go. I speed up for the swim sprint to the beach and finally, I stumble out of the water, realizing I had done it!!! I say a small prayer to my donor and his family.

I look up at the clock, 59:09, I can't believe I had completed it in under 1 hour, I had expected at least 1 hour 15minutes. I am so happy and elated! I head to the marshalling area to see if Paul and Derek had finished. Paul had breezed through in 41:21 and we swapped stories while waiting for Derek, time ticks by, eventually Derek appears safe and sound and we are eager to hear how he got on. 1:21 was the official time, but it was jet-ski assisted as Derek was pulled out of the shipping lanes by the organizers and put back in the water out of the way to finish.

We devour the snacks and drinks at the finish as medal presentations were made to competitors. Paul mentions to the organizers about my achievement and before I know it I am being interviewed. I take the opportunity to stress how important organ donation is; I wouldn't be here without it. There is general amazement that I have come all the way from Australia with my new lungs and finished the swim. I am announced as a winner in my age group for the "physically challenged" category and receive a medal and bottle of "Sharkfest Bloody Red" wine. A good day all round.

Paul, Derek and I celebrate with a night out in San Francisco and the less said about that the better!

**Jon Rolfe,
Double lung transplant and
Alcatraz escapee**



Out of the water at the finish!



The 3 amigos, Paul, me & Derek at the start marshalling area, with Alcatraz in the background!

Special General Meeting 12 February 2013 to consider various changes to the Constitution

Introduction

This is a notice of a Special General Meeting of the Heart and Lung Transplant Trust (Victoria) Incorporated (“the Trust”) to be held on 12 February 2013 at 7.30pm Seminar Room, Ward 5E, The Alfred Hospital, 55 Commercial Road, Prahran VIC 3181.

It has been convened by the Committee of Management of the Trust for the members to consider and, if thought fit, to approve a change in the Constitution of the Trust. This is the only business at the meeting. This notice has been given at least 21 days before the date for the meeting in accordance with the Associations Incorporation Reform Act 2012 and the Constitution of the Trust.

Voting

Members who have paid all moneys due and payable to the Trust, other than the amount of the annual subscription payable in respect of the current financial year, are entitled to vote. Members are entitled to appoint another member as proxy by notice to the Secretary. The form of proxy is available from the Secretary via e-mail at secretary@hlttv.org.au, or via post at PO Box 25036, Melbourne VIC 3004. There has to be at least five members personally present to form a quorum.

Reason for the changes

The Committee of Management of the Trust believes the proposed changes will ensure the Constitution of the Trust is up to date following the new Incorporation Reform Act 2012 that became effective in Victoria on 26 November 2012 and are based on advice received from King & Wood Mallesons.

Resolution

It will be the intention at the meeting to propose a resolution that adopts the above changes in the Constitution of Trust. If the resolution is passed the changes in the Constitution of the Trust do not take effect unless, and until, it is approved by the Registrar of Incorporated Associations. If the resolution is passed, the Secretary of the Trust will, within 28 days of the meeting, apply to the Registrar for approval.

Further Information

Members wishing further information about the meeting or the proposed changes to the Constitution of the Trust are invited to contact the Secretary via e-mail at secretary@hlttv.org.au, or via post at PO Box 25036, Melbourne VIC 3004. Specific wording is available on request from the Secretary and can also be found on the website www.hlttv.org.au under the “About Us/Membership/Constitution change” section.

Proxy form
Special General Meeting of the Heart and Lung Transplant Trust (Victoria) Inc.
to be held 7.30pm 12 February 2013 at
5th Floor Seminar Room ,The Alfred Hospital, Melbourne

I,
(name).....

of
(address).....

being a member of the Heart and Lung Transplant Trust (Victoria) Inc. appoint

(a) *The Secretary of the Heart and Lung Transplant Trust (Victoria) Inc.; or*

(b) *(name of proxy holder).....

of

(address of proxy holder)*

being a member the Heart and Lung Transplant Trust (Victoria) Inc., as my proxy to vote on my behalf at the special general meeting of the Heart and Lung Transplant Trust (Victoria) Inc., to be held on 12 February 2013 and at any adjournment of that meeting.

My proxy is authorised to vote *in favour of/*against the following resolution:

“The proposed changes in the Constitution of the Heart and Lung Transplant Trust (Victoria) Inc. be adopted.”

Signed

Date

**Delete as appropriate*

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 Vic 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. "*

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?