the Circulator

HEART AND LUNG TRANSPLANT TRUST (VICTORIA) INC A0037327C | ABN 68 585 966 022

Summer Edition | 2019 | Issue No. 98

HLTTV: here to assist and celebrate you

President

Welcome to the Summer Circulator, our last edition for 2019. What a year we've had – it's been such a treat to meet and socialise with so many of you at our Easter and Xmas BBQs, and of course our fabulous Silver Anniversary Fundraiser in August.

At our November committee meeting, our treasurer David commented wittily *'I wish I could tell you what I've got planned for next year, but I haven't got 2020 vision.'* We can all look forward to plenty of '20/20' jokes next year – I know I've already had plenty from my optometrist!

The start of a new year is always a time of promise, and a good time to think about priorities for the year. With my husband soon to hit his five-year transplant anniversary, I've been reflecting on the challenges of 'survivorship'. The gift of a second chance also comes with some hefty responsibilities of managing ongoing conditions and challenges.

In 2020, we'll ask members of the transplant community about their biggest challenges after transplant.

HLTTV has already made inroads into the challenge of accommodation through our ***Second Chance Accommodation Program***, and we'd like to go a little further to find out what else could make your lives easier.

Things that have cropped up for my family include:

- Finding 'transplant friendly' GPs, dentists, physios etc
- Coordinating outpatient clinics so that they don't interfere with work commitments
- Going back to work
- Communicating how to be 'transplant friendly' to a new workplace
- Managing/coordinating the administration of transplant life – this has included Centrelink and other paperwork
- Finding 'local' pharmacies that reliably stock anti-rejection and other TX related medications
- Negotiating the permissions required for high volume scripts (such as Slow K)

What about you? I'm keen to hear from members about what would make your post-transplant life better/ easier.

To that end, please email me president@hlttv.org.au with the subject line: *Challenges.*

All emails will be treated confidentially, and de-identified (no names/locations) when included in future discussions.

Throughout 2020, the committee and I will work with the Alfred TX clinics and the relevant peak bodies on exploring solutions to these challenges and sharing them back with the transplant community. We'll also run this 'campaign' on our social media platforms to give more people a chance to have their say.

In closing, the holidays can be a good time of year to reach out to our friends and loved ones with greetings and warm wishes. It can also be a tough time when we think about those who are no longer around to celebrate with us in person.

This Christmas season be kind to yourself and others – we at HLTTV are thinking of our transplant family and wishing you all a fresh New Year filled with beautiful dreams and hopeful goals.

Yours in health and happiness,

Belinda MacLeod-Smith
President, HLTTV

VALE
Graeme Balcombe

The Alfred Transplant community celebrates the wonderful life of Graeme Balcombe of Glengarry who passed away recently.

Graeme (loving husband to Julianne) was universally loved and respected. He was a selfless man who thought of others first and had a great sense of humour. He was an absolute favourite with all the staff in 3East and VAD Clinic.

Graeme – always with a smile, a friendly greeting and a sharp wit. You cared about others and never complained. You will remain in our hearts and thought. Bless you, our friend. (Bruce and Lyn)

Graeme always greeted me with a hug and a smile, and I would comment on how I liked his fashion style. We instantly clicked as good mates as we had the same quirky sense of humour. He would say something funny to cheer me up if I was having a bad day, no matter how bad his day was. Always putting the needs of other people before his own. Meeting 'Gray' has taught me to be a kind and humble person. He's always in my thoughts. (Kaitlyn)

A true friend and gentleman. Sadly gone from our sight but never from our hearts and never forgotten. (Lynn and Rod)

Such a lovely man with a beautiful, generous heart. Always smiling through the good times and the bad. So very glad we met you. (Andrea and Graeme)

Graeme was a very special man with a wicked sense of humour which he maintained even when times were hard. It was an absolute privilege to have cared for him over the years. A true gentleman who I considered a friend! (Julia Rix, Alfred MCS Coordinator)

Three old blokes with their VAD-bags

Secretary

Wow! It's beginning to look a lot like Christmas! It has certainly been a busy time so it's really snuck up on me.

Our Christmas BBQ was well attended, on such a perfect Spring day and full of fun. We had some new attendees and plenty of regulars which was great. We met Josie, from Traralgon, who raised $630 for HLTTV and also funds for Lungitude. Look out for the ad about her Family Fundraiser at a Miniature Railway in February 2020.

Also, Laura Denholm was in Melbourne from Tasmania and it was wonderful to meet the co-author of *"The Carer-Partnering a transplant recipient"* book which Laura and her late husband Carey wrote. They generously donated copies to the HLTTV and we have a few copies left which are free for members, just email me or go through the website for a copy. Laura continues her advocacy and work in the transplant carer space.

Thank you all for coming along. We had an enormous raffle which raised nearly $500, a wonderful knitted doll which Gaylynn's friend had made, who's name we had to guess! Emily's guessing game raised $80. We had Flick's generous "C'gals" again donate $600 from their gatherings to the Second Chance Accommodation Program and generous donations from many others on the day.

Thank You all for your generosity and especially to the caterers, Martina and Adam, and the cooks, John, James and Musa. Delicious!

In November, HLTTV had its Annual General Meeting and a new Committee was elected. Vanessa Scott has been membership officer for 5 years and would like to hand this role over to someone new, so we have a vital role to be filled.

Our 2020 Committee is:

President: Belinda MacLeod-Smith

Treasurer: David Pidgeon

Secretary: Maarit Moilanen

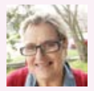
Ordinary members:
Martina McArdle; Sam Ira;
Adam Miller - Communications;
Graeme Klemm - Circulator Editor and
Vanessa Scott: Membership (retiring).

Vacancies are: Vice President; Events; Peer Support and Membership

We are really interested in what YOU would like to do in 2020 so drop us a line! If you have any FUNdraising or project ideas, get togethers, or want to help with our current events, please get in touch.

Don't forget we have Fitness Grants to get you started on your New Year's resolutions!

Have a wonderful Christmas, New Year and summer time!



Maarit Moilanen
Secretary@hlttv.org.au

PS Here's a little summer treat...

Bok Choy Salad

Ingredients:

- 2 bunches of baby Bok Choy, washed well and chopped
- 1 bunch spring onions, chopped
- ½ cup silvered almonds, toasted (or any toasted salad nuts eg pine nuts, sunflower seeds, etc)
- 1 pkt Changs Crispy Noodles (GF ones available). Toasted as well if you like.

You can add other veggies, eg grated carrot, celery, etc.

Dressing:

- ½ cup olive oil
- ¼ cup white vinegar
- ⅓ cup sugar (I reduce this a bit or use 1 tablespoon honey)
- 3 Tablespoons Soy Sauce

Toast nuts and noodles and cool.

Chop all ingredients and add cooled nuts and noodles.

Mix dressing ingredients in a jar and add to salad when ready to serve.

Enjoy!

Post-transplant support comes in all forms

Even the simplest things like catching up for a regular coffee can provide support to transplant recipients who may be finding the transition back to their lives after transplant. The road is quite different for every recipient with medical, social, financial and emotional circumstances unique to each person.

So talking about anything and everything going on in their lives is one way to rationalise some of the challenges they are facing. It's also a way to help each other remain motivated to stay healthy and regularly exercise – a necessity which some find hard to find consistency with on a long term basis.

Transplant recipients Giulia (L), David (L), Ahn (L) and Graeme (H) having a chat at 'Long Lost Friend' Cafe in Adelaide recently.

Committee meetings 2020

(Email secretary@hlttv.org.au for agenda items.

Meeting 1/4 - Tues 11 Feb, 2020
Meeting 2/4 - Tues 12 May, 2020
Meeting 3/4 - Tues 11 Aug, 2020
Meeting 4/4 - *AGM (followed by meeting) Tues 10 Nov, 2020

Meetings are usually held at the Alfred, Fifth Floor Meeting Room at 7.30pm with the Committee meeting in Alf's Café at 7pm for a catch up. ALL WELCOME!

Events

- **Easter BBQ**
  Sunday 29 March 2020
- **Service of Rememberance (Vic)**
  (Last Sat in May, 30th, TBC)
- **Donate Life Week**
  Sunday 26 July 2020
  to Sunday 2 August 2020
- **Donate Life Thank You Day** TBA
- **Christmas BBQ**
  Sunday 29 November 2020
- **Medibank Melb Marathon**
  Sunday 4 October 2020

Shared successes

Imagine being part of a team that gave a 6-year old the gift of breathing without an oxygen bottle for the first time in her life. Julian Gooi embraces collaborating on complex cases to achieve that and much, much more.

The thing that struck me from the moment I was admitted to ICU at The Alfred in 2017, and subsequently underwent VAD surgery, a long recovery and then a heart transplant earlier this year was the number of extremely talented people who had been there for a long time.

Being from Adelaide, I came to discover this place was no stepping stone, this was a destination. A gravitational force that attracted expert medical practitioners at every level of care. The best wanting to be among the best because that's when innovation really starts to take hold.

In this edition of Q&A you meet Julian Gooi, another long-termer in the Heart and Lung Transplant program who just revels in the complex and difficult... because that's just what they do. Solve problems that very few others can.

Q&A

The second in a series of Q&As to get to know some of the key people in the world-leading Heart and Lung Transplant program at The Alfred

Julian Gooi is a Cardiothoracic and Transplant surgeon who has worked at the Alfred Hospital for over 10 years. Graduating in 1996 from the University of Melbourne, he completed his Internship at the Austin Hospital before commencing training in Cardiothoracic Surgery.

It was a two-year training placement at the Alfred Hospital that stimulated his interest in transplantation and complex surgery. In 2006 he completed a Fellowship in Cardiothoracic and Transplant surgery at Papworth Hospital in Cambridge, UK. He joined the Alfred Hospital in 2007 as a consultant. He has a keen interest in Thoracic surgery and lung transplantation.

Do you remember when you made a conscious decision to make medicine your career path, and was there a particular person or event that motivated you?

I don't particularly remember any conscious decision to pursue a career in medicine but had an uncle that was a Doctor and also did work experience at the Royal Childrens' Hospital when I was in high school so I guess I must have had an interest in medicine.

As for surgery, I do remember when I was an Intern and resident liking the idea of having short term goals of surgery rather than being a physician. It seemed to me that with surgery, you focused on a particular surgical problem, worked out how you would solve or deal with the problem and then performed an operation for several hours.

At the end of this period, you knew whether or not it had worked. I liked these short term, focused goals rather than looking at patients charts and dealing with long-term chronic problems. I also definitely liked to do things with my hands.

When did you decide that surgical specialisation was something you wanted to pursue?

From a surgical specialisation perspective, I do remember being told by Cardiothoracic surgeons that I should consider it as a career and had some experience working for such units and liked the medicine and surgery.

I also like the fact that, in a lot of ways, we are wholistic surgeons in terms of the fact that we also need to know and understand complex physiology and medicine and so can manage our complex patients ourselves. Very few surgical units do that.

From the point of view of pursuing Cardiothoracic and transplantation, I did most of my training here at the Alfred and have always liked the complexity of the problem and its surgery. It provides me with the opportunity to really make a difference to people's lives and is also a particularly unique speciality that only has about 30 surgeons around the country.

Can you give some examples of how technology or innovation has improved surgical techniques in lung transplantation in recent years?

We have made great advances in lung transplantation and 5-year survival has improved from around 50%/ 5-year to now almost 75%/ 5-year survival. This has a lot to do with the long-term and aggressive management by the Transplant physicians and the anti-rejection medications and the way in which they manage infection.

From a surgical perspective, the fact that we now very rarely split the breastbone to perform 'clamshell' incisions means that patients no longer have major problems with the healing of the sternum.

The advent of DCD (donation after cardiac death) donors has meant that the number of lung transplants that are performed has increased markedly and now we routinely do 90-100 transplants a year. 10 years ago we did 30-40.

We also have a new lung perfusion device that enables us to perfuse and assess donor lungs on a special machine (EVLP) that allows us to assess and rehabilitate lungs whilst on a machine prior to implanting them in a patient.

Lung transplantation outcomes have greatly improved during the last decade, where do you see the greatest improvements in the next 5 to 10 years?

Improvements in survival will continue to come from improvements and refinements in anti-rejection and antibiotic medications.

Also, the manner in which we assess donor organs and the ability to potentially give donor lungs medications or other treatments whilst on EVLP could mean that the donor organs that we implant are healthier organs.

What role has mentoring played in your career?

I am hugely indebted to my surgical mentors for guiding and advising me throughout my career. Without their support I would never have gotten to where I am today.

Has your Cantonese heritage been pivotal in your medical career?

I am very proud of my Cantonese heritage and my parents are very proud of my achievements. I suppose being migrants and of Cantonese heritage instilled in me a strong study and work ethic that is still very important to me.

What are some of the motivations that have led you to collaborate on research projects and articles?

Working in a multidisciplinary team is very important to me as it exposes you to different ways of thinking and also enables you to make difficult decisions about complex cases and patients.

Because many of our cases are difficult, have been rejected by other units or have many complexities, working in a team means that decisions are shared. This also fosters innovation and hence research.

The surgeries you do can be incredibly long and complex. What are some of the ways you balance your life outside work?

Yes, the procedures can be extremely long and complex and take up a lot of both physical and emotional energy.

Family is very important to me and it is great to be able to go home and shed the title of surgeon and become a Dad and a partner to my family.

They are a very important way of grounding me. I do particularly like catching up with friends and family, love food and wine and also have a great weakness for vinyl records!

In a general sense, are there any lung transplant surgeries/patients that have particularly resonated with you?

I remember virtually all the lung transplants that I have performed over the last 10 or so years as each of them have meant that someone has a chance at a new life.

The paediatric lung transplant cases that I have been involved in have particularly resonated with me. I do recall one especially, as she was 6 years old at the time and had never been off oxygen in her short life.

We performed a lung transplant and the next I heard from her she had been off to Hawaii snorkelling with turtles!

I recently caught up with her here at the Alfred and she is now a wonderful 12 year old going to school and enjoying life. That brought a tear to our eyes.

Meet some new Alfred staff...

Kerrie Smart
Allied Health Assistant and central contact for HLTTV SCAP
k.smart@alfred.org.au

Andy Allen
Cardiac Heart Failure, Heart Transplant, and Trauma Social Worker
andy.allen@alfred.org.au

The Social Work Department at The Alfred plays an important role assisting transplant patients navigate their journey before, during and post surgery with advice and support on a large number of issues including the HLTTV Second Chance Accommodation Program for post-transplant patients and carers.

"I am thrilled to be working within the Cardiac Heart Failure and Heart Transplant space, assisting patients with adjusting to their diagnosis, navigating supports for patients as well as their families, and counselling for patients pre/post-transplant as well as their carers."

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HLTTV Second Chance Accommodation Program

Since May 2012, HLTTV, through our *Second Chance Accommodation Program,* have been thrilled to partner with the *Park Regis Griffin Suites* to provide affordable, accessible and practical accommodation for regional transplant recipients.

The Program provides eight one-bedroom apartments for the use of transplant recipients.

Situated between Melbourne city centre and St Kilda Beach, the *Park Regis Suites* feature a range of different accommodation options, an on-site cafe-bar and a tram practically at the front door.

We highly recommend the *Park Regis Griffin Suites* and the *Stay Well Hospitality Group.* For those looking for accommodation close to The Alfred make sure you check with the *Park Regis* for any available discounts.

Park Regis Griffin Suites
Phone (03) 8530 1800
Location 604 St Kilda Road, Melbourne
Email griffin@parkregishotels.com
www.parkregisgriffinsuites.com.au

StayWell
PARK REGIS
Leisure Inn

The Second Chance Accommodation Program is administered on a day-to-day basis by The Alfred Patient & Family Services Department (social workers).

Any enquiries about availability should be directed through Social Workers – Jane Harris (Lungs) (03) 9076 2000 or Andy Allen (Hearts) (03) 9076 3026.

Some people like to wear their heart on their sleeve!

Everyone that goes through a major health trauma has their own way of responding to it.

Some like to get involved with organisations and volunteer their time to assist others going through similar challenges. Others like to advocate for a cause or organisations like 'Donate Life' or 'Lungitude'.

One way of getting people to think about their own health more is to prompt them into that process by a suggestive slogan on a T-shirt.

Rod from Geelong

Kaitlyn from Mildura

SPECIAL OFFER

HLTTV would like to offer any transplant recipients (both heart and lung) the opportunity to spread 'their' word by assisting them produce the artwork for a T-shirt, windcheater, coffee mug or cap.

If you would like to discuss your idea, please send your contact details to circulator@hlttv.org.au and we will ring you to get the ball rolling.

In return, all we would ask is a donation to the HLTTV of $20 to assist us with our Second Chance Accommodation Plan which helps post-transplant patients with accommodation near The Alfred while they recuperate.

Step 1: you email us with your details

Step 2: we'll contact you to discuss and forward you bank details for HLTTV

Step 3: you make a $20 donation to the HLTTV bank account

Step 4: we'll come up with the artwork for your idea and email you the print-ready artwork to take to your local screen-printer

Step 5: you start using your new product!

TRANSPLANT 2019 ANNIVERSARIES

HEART

NOVEMBER
Paul Allen, 2011
Jennifer Ball, 2009
Sam Di Natalie, 2010
Fulvio Filipponi, 1993
Bernice Hallam, 1996
Adrian Sayers, 2007
Nadine Towler, 2015
John Turley, 2002

DECEMBER
David Ash, 2008
Don Browne-Kerr, 1997
Jane Buxton, 2014
Greg Dartnell, 2004
Peter Grimsted, 2016
David Hales, 1998
Jack Jones, 1989
Stephen Patching, 2017
Helen Rankin, 2011
Peter Stonham, 2016
Rodney Whitford, 2011

JANUARY
Howard Bear, 2013
Kylie Chappell, 1992
Carol Darroch, 1992
Simon Eaton, 2011
Mark Ginn, 1993
Andrew Hunt, 2008
Peter Ketelaar, 2017

LUNGS

NOVEMBER
Lynette Alexander, 2015
David Biram, 2010
Phillip Buckland, 2009
Ian Casey, 2008
Bob Crockett, 2015
Ken Fletcher, 2016
Paul Thomas Gloede, 2012
Len Hain, 2002
Anna Modlin, 2010
Alan Picone, 2015
Karen Pritchard, 2015
Nikola Radocaj, 2002
Terry Rocks, 2016
Noel Sandrazie, 2016
Simone Volkman, 2016
Peter Weidl, 2014

DECEMBER
Kevin Avery, 2015
Ilene Henderson, 2015
Tony Hyams, 2015
Wendy Jenkins, 2006
Vic Reynolds, 2018
Alison Walters, 2004

JANUARY
Josie Barrett, 2019
George Bouios, 2008
Ann-Marie Dunbar, 2014
Brooke Evans, 2018
Elizabeth Johnson, 2013
Leslie Miller, 2016
Patricia (Sue) Newell, 2017
Philip Stephenson, 2003
Chris Teese, 2014
David Thurbon, 2019

Yes, life can be vibrant after transplant

Lung transplant recipient Ahn Nguyen (2019) is making the most of her post-transplant life back in Adelaide.

A long-time fan, Ahn recently had the great pleasure of meeting global musical superstar Rob Thomas of Match-Box Twenty fame at one of his recent concerts.

Reaching out to your donor's family

Many transplant recipients make use of the opportunity to reach out to their donor's family once they have recovered from their surgery.

There is no right or wrong way to communicate your feelings about the gift of life they have given you, but many people write a letter of thanks. Other ways people pass on their thoughts are through thank you cards and heartfelt poems.

An example of one such message...

How would I thank you
Would I stumble on my words
Rambling trying to make sense
Of what your gift is worth
Do I tell you about
All the things I can do
I can run, I can jump
Even ride a bike too
Do I tell you my daughter
Has never been happier
Knowing she has her mother
Living without barriers
Can I tell you I'm sorry
For your loss and your pain
Can I tell you
Your gift has let me live life
Again.

Talk to your Transplant Coordinator if you would like a brochure to assist you putting your written communication together.

Alfred transplants 2019

28 83

Note: these figures are for the period January 1 – December 10, 2019

GiveNow

Give more, give smarter, give better, GiveNow!
Donations to the Heart and Lung Transplant Trust (Victoria) are fully tax deductible and easy to do using the website below.

GiveNow.com.au

2019 HLTTV Christmas BBQ

Our annual 'recipient' group photo of those attending our BBQ











The 2019 HLTTV Christmas BBQ was another fabulous event, celebrating life and the year that was.

Melbourne really turned the weather on for us as over 60 people came together and relaxed in the dappled shade of Fawkner Park.

The food was delicious, the raffle bountiful and the Christmas Carols plentiful (and no, it wasn't too early for *'All I Want For Christmas Is You'*)

The highlight was seeing over 25 organ transplant recipients gather for our annual group photo – a touching reminder of why we do what we do.

Thank you to everyone who joined us and helped make the BBQ a success... from setting up, cooking, selling raffle tickets and donating items for our raffle. All of which helped us raise over $1,500!









Appreciating life!

I'd heard of Alpha males before, but Alpha-1? Craig Wood succumbed to a rare genetic disease in his late 40s and his story is telling...

In March 2018 I was lucky enough to receive a double lung transplant at The Alfred that has transformed my life and given me a second chance.

As a child I was athletic, played football and cricket and later golf and baseball. I was pretty fit and there was nothing that pointed to having any underlying health problem.

On a family holiday to the snow when I was 46 I struggled in the high altitude with my breathing – this was the first time I noticed anything untoward.

I consulted my doctor and had precautionary x-rays and tests resulting in a referral to a Lung Specialist.

I had a Lung Function test in September 2008 at Monash in Clayton. The result was 38%. This was to be the first in a series of annual tests for the next decade in which time the result had decreased my lung capacity to 22%.

My 'quality of life' was now being severely effected. I couldn't walk very far before I would start 'puffing'.

The turning point for me was a referral to The Alfred Hospital Lung transplant Team for initial consultation and subsequent assessment.

The diagnosis for my diminishing capacity was alpha-1 anti-trypsin deficiency. It is a genetic disorder that results in an estimated 1:2,500 Australians inheriting a condition which results in too little alpha-1 anti-trypsin being produced and released into the blood stream by the liver, meaning the level of alpha-1 anti-trypsin in the lungs is too low to protect against enzyme damage to lung tissue.

The assessment process is conducted over three days and requires a two-night admission.

Following my assessment and subsequent approval for a transplant I was extremely fortunate to wait only six days to my call from the Transplant Coordinator at 6.00am on a Sunday morning. I arrived, with my family, at The Alfred at 7.30am.

Craig Wood and wife Billie-Jean enjoying his new lease on life

The work-up and wait...

Lung transplant assessment is a comprehensive process that includes meeting with:

- Pharmacist
- Occupational Therapist
- Transplant Coordinator
- Anaesthetics review
- Dental Clinic
- Dietician
- Physiotherapist
- Social Worker
- Chaplin
- CTHR Surgeon

There is also a requirement to have a number of tests:

- Carotid Duplex
- Dexa Scan
- VQ Scan
- CT Thorax
- Spot Urine test
- Fasting
- Lung Function
- BIA Assessment
- Echocardiogram
- Multi-vial blood test

There is a final, more invasive test that takes place outside the 'work-up' meetings:

- Angiogram

Once 'approval' has been given by the transplant team following all of the tests, your blood type is issued to the ARCBS (Australian Red Cross Blood Service) and provided nationally for a compatible donor match.

Then it is a matter of waiting for an appropriate donor match to occur.

It turned out to be a long day of anticipation when the head of the Transplant Team, Professor Greg Snell, approached me at 5.30pm to advise that the transplant was ready to proceed. Within 30 minutes I prepped for surgery, met with the anaesthetist and surgeon and said my 'good-byes' to my family before being wheeled into theatre.

Later that evening my wife received the great news that surgery had been successful and I was now in ICU.

I spent three and a half days in ICU with outstanding care from the attending nurses and doctors helping me through the recovery process and pain relief.

I was able to start eating after three days – just hospital sandwiches – but they were enjoyable on an empty stomach. I was also able to get a glimpse of the surgeon's handiwork, along with the drains and bruising.

It was liberating to get out of bed and sit on the chair.

The 'puff exercise', folded towel 'teddy' and epidural were godsends to get me through ICU and up to Ward 5 East for recovery and then eight weeks of 'Rehab' (should have been 12 weeks but my recovery was excellent).

Clinic, education sessions, regular bloods, gym, regular mobilizing, Lung Function tests and Bronchoscopies were the backbones of the rehab regime.

Add in getting used to food safety, preparation hygiene and the ever-present and critical 'medication program' and life just got pretty busy.

Thankfully, for me, life is getting back to a 'new' normal with plenty of regular exercise and making sure I feed my new lungs with good food and outdoor air.

I am indebted to all of the incredible professionals and staff at The Alfred, along with my wonderful donor family. My entire family says *thank-you* for the second chance I have with them.

I am now a board member of Lungitude Foundation where we hope to improve survival rates and outcomes for lung transplant recipients and their carers.

Heart to Heart House, Barmah Vic

...a great place to relax

For bookings and information

Martina McArdle 0409 957 492 | **Laraine Anderson** (03) 9770 7197 or 0418 599 745

ALL ABOARD AND RAISE SOME MONEY FOR THE HLTTV

The Gippsland Model Engineering Society and Miniature Railway Club is having a public run day with proceeds going to the HLTTV. *Get on board!*

Save the date

Sunday 23rd February, 2020
Time 12.00 – 4.00pm
Cost $3.00 per ride
Venue: Newman Park,
Peterkin Street, Traralgon

Get in touch with the Ballarat Support Group

The Ballarat Transplant Recipient Catch-Up Group is the only group of its type within Victoria.

It provides recipients and their carers the opportunity to obtain information and education from health professionals in a relaxed and informal group environment and is endorsed by the Heart Lung Transplant Trust of Victoria, affiliated with the Alfred Hospital.

Members of the group come from all around Ballarat and surrounding areas.

If you live in or around Ballarat and are interested in being part of the group or find out about upcoming meeting dates and locations, please contact:

Donation Nurse Specialist
Larna Kennedy on 0411 323 006
or larna.kennedy@bhs.org.au

Donate NOW

HLTTV

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

Name

Address Postcode

Telephone Mobile

Email

Donation $

Donations over $2 are tax deductible.

Please return this form to:
Treasurer, Heart and Lung Transplant Trust (Victoria) Inc
PO Box 25036
Melbourne 3004 Victoria

You can also visit http://www.hlttv.org.au and look under *'Quick Links'* and choose one of the *'Donate Now'* links

REGISTERED CHARITY
acnc.gov.au/charityregister

Alternate realities

From barking dogs to butterflies, birds and singing songs, many people experience hallucinations post-transplant and VAD surgery.

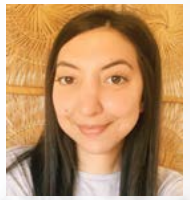
The human mind is a peculiar thing. It has a great capacity to solve the most complex problems and the creativity to invent the most beautiful art and products. It can also conjure the most vivid, and strangely 'real' dreams, especially when under the influence of pain-killing and anti-rejection medications.

Everyone's experience of this is very different as you might imagine, with their physiology and life experience being unique to themselves.

I met Glen while I was recovering in 3East after my VAD operation in 2017 who described an interesting hallucination of riding a motorcycle on a jungle road in South America. OK, that sounds plausible enough, except for the fact that he had never ridden a motorcycle before. What made this story even more interesting though was the fact that he got to speak to another recipient who had virtually the same hallucination as himself... motorcycle, South American jungle. Spooky. They eventually celebrated this unusual connection by purchasing matching Harley Davidson rings from the gift shop at The Alfred to remind them of their 'ride'.

Others have recollected towels changing place in their room, feeling that the curtains in Alfred"s ICU are like the entrance to Bedouin tent and other curious peculiarities.

Nicole (Heart 2018)



Unbeknown to me at first, my transplant surgery didn't go as smoothly as the doctors and I had hoped, but I remember eventually opening my eyes and feeling a sense of relief that my surgery was a success and in the words of Elton John himself, I was *"as high as a kite"* and had absolutely no complaints. The mixture of anaesthetic, super strong pain killers and my new anti-rejection medication did a number on both my body and my mind.

Like many transplant patients, I experienced hallucinations, which apparently is quite a common occurrence after a major surgery.

My first memory post-transplant was that I was laying in the hospital bed, in my shared room, surrounded by HUNDREDS of tiny Dalmatian dogs. They were jumping onto my bed, licking my legs and howling at my bedside. If that wasn't bad enough, they all had string with balloons attached to their tails which would continuously be in my way. It became so infuriating that I asked my mum, as nicely as I could, to *"get these bloody dogs out of my room"*. After assuring me that she did, I would look around and they would still be there. What was strange was that the other three patients in my room didn't even seem to notice them. This confused me even more. To be completely honest, because I missed my pets at home immensely, seeing the dogs in my room became a comfort that I relied on. I don't remember how long this went on for exactly, but I would guess just a few days, although it felt like an eternity at the time.

My second hallucination was far worse than the dogs. My mum had just left the hospital to rest and as she shut the door behind her, the room turned into a bar. Music, dimmed lights, bar staff – the works! I saw doctors and nurses head there to get drinks and have a dance after their shift. Meanwhile, I was in there too, in my glamorous white hospital gown, still in bed unable to move. I was exhausted and all I wanted was to sleep but everyone was so ridiculously loud.

The easiest way to explain it was like a corny romantic comedy scene, where people meet up at a bar after work, having a boogie to an overrated 90s pop song, laughing loudly and acting frustratingly over the top. The next morning, in my aggravated state, I recognised one of the nurses from the 'bar' and I told her how annoyed I was that they were being so loud and that it was pretty inconsiderate considering we are in a hospital full of sick people. The poor nurse gave me a confused look and a smile and said *"I promise to head straight home tonight, and I'll let the other nurses know too"*. That was the last time I saw the bar.

Bruce (VAD 2017, Heart 2018)

My hallucinations only occurred after having had the LVAD surgery. I do not recall any hallucinations after the heart transplant.

The first episodes simply consisted of 'vivid blue' two-dimensional rectangular shapes appearing, then disappearing, from my vision. The different sized shapes, seemingly around half a dozen in any given episode, kept coming in and out of my vision. At that time they were a regular part of my 'day' and would come and go at seemingly random times.

The second hallucination is rather more difficult to explain but I will give it a shot. Picture this, I was in a small field of green grass, there was a small tent in the middle of the field, the daylight was fading quickly, I was riding a push bike, one of my family members was in the scene and, very importantly to this hallucination, there was a steel pole sticking vertically out of the ground by about 300-400mm.

The pole seemed like the type that they use in construction concreting. I rode around on my push bike, noticing the family member and avoiding the tent when a distinct buzzing/humming sound started. As this seemingly real sensation occurred, the push bike stopped and, losing my balance, I started to fall directly towards the steel rod. It seemed as though I was going to be impaled through the chest. The buzzing stopped and, thankfully, I ceased falling and never actually ended up on the 'rough end of the rod', although I did come very close. Sometimes it seemed that the episode would be on 'repeat'. My recollection was of having this hallucination on regular occasions. At the time, these episodes were very disturbing.

Recalling this in the early days was quite uncomfortable, and although I've never forgotten about it, I'm glad to say that as time has passed things have settled down and they don't come to mind that often.

Kaitlyn (VAD 2017, Heart 2019)

I seemed to have a lot more hallucinations in ICU post-Vad surgery then I did post heart transplant surgery

In ICU post-vad surgery I thought I was a singer having a concert and the people coming to my room were fans coming to watch me perform.

I also thought that one of the doctors was Danny Zuko from *Grease* and I was apparently singing songs from that movie.

In ICU post-heart transplant I woke to see the figure of a person in the corner of the room. I pointed at it and told my dad that it was me and then I went back to sleep. He later said that I had commented that I was born in 1985 (actually not the case).

For a few months following my heart transplant I had a recurring dream that I was at a busy train station and got on the train in a hurry because I was running late to get home to cook dinner for my family. The train driver wouldn't stop to let me off then everything would go black and I would wake up.

Giulia (Lungs 2019)

In our post-transplant education sessions, the social worker told us that due to the cocktail of drugs we were on, virtually no-one escaped hallucinations while in ICU so not to be surprised.

She related a story to us from a patient who asked her why the nurse would always squat at the end of his bed to wee. It turned out that the nurse was squatting down to empty out his urinary catheter into a container!

I had a tumultuous and longer than expected time sedated in ICU so wasn't fully aware until about Day 19, and even then, I was disorientated, confused and paranoid for 2 to 3 days having just come out of what I called my 'alternate' reality. I later found out that this alternate reality WAS my hallucination. When I finally got around to reading the daily posts my mum and sister wrote while I was in ICU I could see where they fit into my alternate reality as I guess I was aware enough at times to incorporate the reality into the alternate reality.

In my 'alternate' reality I was on a state-of-the-art hospital ship that traveled around the world treating people and it was docked in Melbourne! I was a patient having a ground-breaking lung surgery to treat my Pulmonary Hypertension while waiting to have a lung transplant. After the surgery I met a freakishly brilliant yet strange doctor who told me he would get me a lung transplant. As he was planning it all out it turned out that IF he let one of his family member's spouse die, I could have their lungs. I refused to be a part of that plan and in the end the family member found out and put a stop to it themselves. Thank goodness because I was absolutely horrified.

By my 3rd 'waking' day I began to realise I was in a real hospital and was able to mouth to the doctor *"Did I have a transplant?"* Luckily, he could lip read, and perhaps I was getting better at mouthing my words, and he said *"Yes! You had a transplant over 20 days ago!"* I silently raised my eyebrows in surprise. Back to full reality.

Gordon (Heart 2018)

My main hallucination was a strange wallpaper that consisted of a purple and brown giraffe pattern over everything and it moved, with the brown patches constantly changing shape. I could make out everybody's shape, the shapes of the beds and furniture but no details due to the 'wallpaper' covering them all.

Other hallucinations consisted of me being at the controls of an aircraft flying, and I remember being quite unhappy because I knew I didn't know how to fly or land. The giraffe pattern wallpaper then came back and stayed most of the time apart from when the blue curtains became animated with leaves blowing in the wind.

I also saw an image of Jimmy Hendrix (it might have been Bob Marley) with marijuana leaves floating out of his head as well as fish swimming in the ocean.

Hallucinations are very common in the early days after major surgery, such as heart or lung surgery. It's estimated that up to 40 per cent of people report hallucinations and other aspects of delirium following some types of surgery. They usually last for a few days and then get better, but can be worrying and confusing for yourself and your visitors.

Things that make hallucinations more likely include anaesthetic drugs, strong painkillers, the noise of the intensive care unit and confusion as to whether it is day or night. Hallucinations may be worse at night when lights are dim.

Scientists think these hallucinations may be linked to the inflammatory response in the body after complex surgery. This is your body's response to injury and its first step towards healing – similar to the swelling when you sprain your ankle. But after complex surgery this happens across your whole body and the hallucinations are just a symptom of the brain not working perfectly.

It is believed people who have long complex surgery are more prone to hallucinations than patients having less invasive surgery because the operations take longer, so they are under anaesthetic and on the heart-lung bypass machine for longer.

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treasurer@hlttv.org.au
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Lung recipient Josie Barrett and husband Trevor benefitted from the HLTTV SCAP assistance and wanted to 'give back' to say thanks.

HLTTV takes care of business

It was a great relief to us when we were told it was all taken care of by the HLTTV.

The HLTTV *Second Chance Accommodation Program* assists a growing number of regional and interstate patients with accommodation close to The Alfred post-transplant.

This financial assistance can change the entire recovery process from financially very stressful to one in which the patient and their carer can focus on the most important issue – the physical and mental recovery from long and complex life saving surgery.

Josie Barrett was able to take advantage of the SCAP after transplant.

My name is Josie Barrett, and earlier this year I received a double lung transplant. As with most patients from regional areas, my husband Trevor and I needed to live in Melbourne for twelve weeks post-transplant.

On the morning we got the call from the lung transplant coordinator, the last thing on our minds was where we would stay. It was a great relief to us when we were told that it was all taken care of, that HLTTV had organised accommodation at the Park Regis on St Kilda Road, just one kilometre from the Alfred Hospital and with very minimal cost to us. Now we could concentrate on recovery.

We wanted to contribute in some way to express our gratitude for all the support we received during our time in Melbourne, so on the 12th of November we held a morning tea in our town of Traralgon. It was a huge success, we raised $1,260, half of which was donated to the Lungitude Foundation and the other half to HLTTV.

In February next year The Gippsland Model Engineering Society and Miniature Railway Club, with who my husband Trevor is a member, has pledged a donation from their public run day.

The club has a number of trains including Steam Electric and Diesel engines. They run on a 1.1 km track and the ride goes for nine minutes. The track is situated in the beautiful Newman Park in Traralgon. There are BBQ and toilet facilities and a very modern play park – the perfect place to enjoy a day out with your children grandchildren and friends while at the same time supporting a very worthy cause.

Save the date
Sunday 23rd February, 2020
Time 12.00 noon until 4.00pm
Cost $3.00 per ride
Venue: Newman Park,
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RECIPIENT
(Please complete information regarding Transplant Type, Operation, Month and Year – this allows us to celebrate transplant anniversaries if you consent below).

	Month	Year
Lung(s)		
Heart		
Heart and Lung		
Other *(please specify)*		

Are you happy for this information to be included in the *'Transplant Anniversaries'* section of *'the Circulator'* newsletter annually? ☐ Yes ☐ No

OR **Pre-transplant** (Waiting list)
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Membership for Pre-transplant members is free. An annual fee of $15 applies to all other category of member. A membership reminder will be included with the Winter 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
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Melbourne 3004 Victoria

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Please visit http://www.hlttv.org.au and follow the *'Membership'* links.

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