

the Circulator

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

Autumn Edition | 2020 | Issue No. 99

8 TRANSPLANT RECIPIENTS SHARE THEIR STORIES IN
NEW VIDEO SERIES. **FIND OUT MORE ON PAGES 8-9**



Coronavirus Safety Tips

Immune-suppressed people are one of the
at-risk groups in the community so make
sure you source up-to-date information



see page 3

President's message

Welcome to this Autumn edition of the Circulator – we do hope you're enjoying the new look and exceptional content being pulled together by our editor, Graeme Klemm.

I personally feel the *Circulator* is getting better with every edition, so please continue to share your stories, and requests for content with Graeme by emailing circulator@hlttv.org.au

Scott Moorhen's story of life after transplant will strike a chord for many of you, and our Q&A interview with cardiologist Angie Leet provides some unique clinician insights.

We just love hearing from the Alfred teams, and are working hard for future editions to profile a cross-section of the staff who play such a huge role in our lives. Who would you like to hear from?

We're experiencing some changes in our committee, with the departure of Vanessa Scott, our hard-working membership officer.

We sincerely thank Vanessa for her work as membership officer which she juggled along with being the 'webmaster' for the HLTTV website and an overall valued committee member. The committee thanks Vanessa for her dedication and hard

work and wishes her many more travel adventures.

I'm very excited to welcome Petra Brosch (see page 14) to our passionate team. She has volunteered to take Vanessa's place as our new Membership Officer.

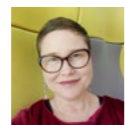
Our most recent committee meeting was quite an adventure, with members putting in a 'full day's work' by participating in a focus group before our meeting.

As the peak peer-support group for heart and lung transplants in Victoria, HLTTV was invited to contribute carer and consumer perspectives to a review of transplantation services in Victoria.

The review includes consideration of access, activity, efficiency and effectiveness and we look forward to sharing more about review results when they're available.

Your transplant journey is a very individual one, but by learning from each other we can help improve the system for current and future patients and their families.

Wishing you all good health and happiness.



Belinda MacLeod-Smith
president@hlttv.org.au
or 0414 582 945

Are the Australian Transplant Games another step on your journey?

The Transplant Games are a fantastic celebration of the gift of life.

The Games are a way to set health and fitness goals for transplant recipients, as well as an opportunity to be part of a wonderful community. The Games are centred around saying thanks for organ donation and promoting transplantation to Australia and the World.

While we have some elite athletes that attend the Games, they are by no means an elite sporting competition. The Games are about participation – getting involved, making friendships that will last years, and having a go.

The next Australian Games will be held in Launceston, Tasmania from the 27th September – 3rd October 2020.

The next World Transplant Games will be held in 2021 in Houston, Texas, USA.

If you want to talk to someone about the Transplant Games and how you can get involved call Julie Edwards in the National Office on (02) 9922 5400, or email Transplant Australia's National Sports Administrator at matty.hempstalk@transplant.org.au

Secretary's message

Happy 2020 everyone! What a crazy summer we've had with fires, smoke, floods and widely varying temperatures.

I hope you've all managed OK. Thinking especially of those of you and your communities who have been directly impacted by summer's tragic events.

We've had our first committee meeting for the year and are all looking forward to a fun filled year supporting our members. Let us know if there are issues you are interested in.

Our Easter BBQ was scheduled for Sunday 29th March, at Fawkner Park, but the HLTTV Committee have taken an early and difficult decision to cancel this get-together due to the uncertainty surrounding the increasing impact coronavirus may have for our community. It is very important to keep our immune-suppressed members safe.

The Committee are planning a larger social event and maybe some other smaller get-togethers during the year. If you would like to help our small group organize an event, have some ideas to share or would like to run a fundraiser yourself in your area and want some help, please get in touch. We can advertise it for you too.

Our 2020 Committee Meetings are listed in the column opposite. Come along and meet the Committee at Alf's Café at 7pm with meetings in the Fifth Floor, Ward 5 East, Seminar Room, commencing at 7.30pm.

Please feel free to contact me with any questions, ideas or comments.

Keep well and enjoy this milder weather.

Maarit Moilanen
Secretary@hlttv.org.au
or 0400 190 356



The Alfred Hospital has suggested ways to reduce your risk of coronavirus (COVID-19)

- Wash hands often, particularly before eating, smoking and after using public amenities. Use soap and running water, for at least 20 seconds. Dry with paper towel or hand dryer.
- Try not to touch your eyes, nose or mouth.
- Cover your nose and mouth with a tissue when you cough or sneeze. If you don't have a tissue cough or sneeze into your upper sleeve or elbow.
- Isolate yourself at home if you feel sick. If you take medication ensure adequate supplies.
- Phone your GP first if you need medical attention. They will tell you what to do.
- Continue healthy habits: exercise, drink water, get plenty of sleep, and now is the time to quit smoking. Call the Quitline 137 848.
- Don't wear a face mask if you are well.
- Buy an alcohol-based hand sanitiser with over 60 per cent alcohol.
- Get the flu shot (available April).
- Shaking hands is optional!
- Try to maintain a distance of at least one metre from people who are coughing or sneezing.

www.alfredhealth.org.au/news/novel-coronavirus/

Please keep up-to-date with Federal and State Health Department guidelines surrounding the prevention, diagnosis and treatment of COVID-19, especially immune-suppressed and at-risk people

www.health.gov.au/health-topics/novel-coronavirus-2019-ncov

www.dhhs.vic.gov.au/victorian-public-coronavirus-disease-covid-19

Members of our transplant community should continue to listen to the advice of the medical specialists and continue to avoid any unnecessary risks.



There are creative people... and then there's Eric

Taking meds in our household has never been dull. As a boy, Eric played with his food and it still continues today! writes Jane Foster.

Are they the building blocks of life... it is food for thought.

Eric Foster had his Lung transplant at The Alfred in 2019. Jane Foster still has a knowing smile on her face.

Committee meetings 2020

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

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, Ward 5 East, Seminar Room at 7.30pm with the Committee meeting in Alf's Café at 7pm for a catch up. ALL WELCOME!

HLTTV Member Events

- **Service of Remembrance (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

Circulator content deadlines

- **Second quarter** – Fri 15 May
- **Third quarter** – Fri 14 Aug
- **Fourthquarter** – Fri 13 Nov

We'd love to hear about your experiences pre and post transplant. Everyone is welcome to contribute to The Circulator. Send contributions to circulator@hlttv.org.au

The Transplant Games - the inspiration, the celebration

BREAKING NEWS

The Board of the Australian Transplant Games have advised that due to the uncertainty surrounding the Coronavirus (COVID-19) pandemic and Federal and State Government advice and regulations a decision whether the 2020 Australian Transplant Games in Launceston will proceed or postponed will be made in May. For further information or updates, go to <https://transplant.org.au/australian-transplant-games/>

australian transplant games 2020
LAUNCESTON

SUNDAY SEPTEMBER 27 TO SATURDAY OCTOBER 3 - TASMANIA

Always the helper

My personal experience as a patient under Angie's care at The Alfred was complete confidence and 100% buy-in to her advice. Her calm demeanour belies a steely determination to succeed. Every patient. Every day.

There are many people who walk the corridors at The Alfred that make a strong impression when you meet them. They have a particular empathy that defines their approach to communicating with their patients that sets them apart from others.

In this edition of Q&A you meet one of those special people – Dr Angeline Leet, the Deputy Director and Head of Echocardiography in the Department of Cardiology. She is a full time cardiologist in the Heart Failure & Transplant service at The Alfred.

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 decided I wanted to be a doctor when I was 9 years old. My father had cancer and post treatment, recurrent headaches. I tended to him and helped him feel better. I liked helping anyone who was unwell and this grew over time.

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

I loved everything I did in medical school and in my clinical rotations as a young doctor. I was going to be whatever specialty I was attached to at the time. It was only during a rotation in Cardiology as a resident, when I accompanied a patient to the catheter laboratory and saw the immediate effect of life-saving coronary angioplasty that I was completely swayed to Cardiology. Little did I know then that it was only a "tip of the iceberg" part of the patient's problems.

And more recently Echocardiography?

Echocardiography to me represents a fabulous jigsaw puzzle of a problem, waiting to be put together and solved. Everything you need to help diagnose a patient's cardiac condition is right there in front of you. More recently, as the Head of Echocardiography, helping our wonderful

by Circulator Editor, Graeme Klemm

Q&A

The third 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



Angeline's expertise includes echocardiography, management of acute and chronic heart failure, mechanical circulatory support both acute and particularly long-term ventricular assist devices and heart transplantation. She graduated from Monash University, Victoria. She completed cardiology training at Monash Medical Centre with Fellowships at the Royal Melbourne Hospital and The Alfred. She spent a year in Bougainville, Papua New Guinea as a doctor with Australian Volunteers International and returned to the Heart Failure & Transplant service at The Alfred, Melbourne in 2004 where she has remained since.

She has particular interests in the long term management of patients with ventricular assist devices, and the transition of paediatric cardiology and heart transplant patients to The Alfred, with a dedicated Young Adult Heart Transplant Transition Clinic within the Heart Failure and Transplant service.

echocardiography and physiologist team optimise the Echocardiography Service at The Alfred has been a deeply enriching and learning experience. I love learning new things, new concepts, new approaches to bringing out the best in people – staff members, colleagues, and patients. This new role has given me all that.

What was the pathway that brought you to The Alfred?

I always felt there was more to managing heart failure during my early training years. As the Echocardiography Fellow at The Royal Melbourne Hospital, after I finished my Cardiology training, I met a Cardiologist who had spent time with the Heart Failure team at The Alfred and recommended I make contact with the team. I've stayed ever since.

You have a special interest in ventricular assist devices. What led you to this focus area?

Ventricular assist devices are an essential management option for patients who otherwise might not have survived to heart transplantation. My particular interest stems from the detailed knowledge required about the devices to best optimise the patient's clinical status. Helping the patient and their family transition to independent living with a ventricular assist device and be the best they can be in readiness for heart transplantation remains one of my greatest joys.

I have heard about wi-fi VADs and 3D printed hearts in media discussions. Do you have an insight to the future direction of VADs and Transplants in Australia?

Wi-fi and totally implantable ventricular assist devices are coming. Great research continues in this field. It will be at least 5 years away, however. 3D printed hearts – we're not quite there yet.

Has mentoring played a role in your career?

Absolutely – I have had great mentors throughout my career, who have guided

me to be the clinician and person that I am. I continue to grow as a clinician and person because of them. I hope to help more junior clinicians as I have been helped and guided.

What are some of the motivations that have led you to have a particular interest in paediatric cardiology and involvement in the Young Adult Heart Transplant Transition Clinic at The Alfred?

Adolescence and the transition from paediatric to adult care is a daunting time for patients and their families, who have literally grown up being managed by a small paediatric cardiology team, who they have trusted over the years. We know the outcomes of young patients who are not adequately guided and managed through this time are poor.

It is a time of fluctuating relationship dynamics, developing more independence from parents, new jobs, and therefore needing to learn to manage their own medical conditions.

I really enjoy forming relationships with them and have them trust me over time, to help them navigate this potentially difficult period. Seeing the patients thrive, manage their medical conditions, medications, appointments independently over time fills me with great pride in their achievements.

You must see some incredibly challenging cases, in a general sense can you give an example of any successful outcome that may have surprised you?

We managed a very sick patient in intensive care who many did not think would survive. We stubbornly kept trying and they miraculously survived. We are constantly reminded of the very delicate balance of life, quality of life and death.

Outside the extensive professional reading you are required to do, is there a genre or author that you like to relax to?

I don't have time to read for pleasure now – but I used to love science fiction. Now I enjoy reading with my son – we love this special time every night.

Regarding your work and patients, what is the one thing that puts a smile on your face?

Seeing a very sick patient and their families get through their darkest days and not only survive, but most importantly, thrive.

If there is an Alfred staff member you'd like to read about, contact The Circulator at circulator@hlttv.org.au and we'll try and feature them in a future edition.

VALE

Phil Stephenson

My husband Philip had a double lung transplant in January 2003.

Although the transplant was successful, unfortunately Phil contracted Lewy Body Dementia in 2013.

Even though his lungs were working well on very low doses of medication, he passed away on the 7th February this year.

Phil would have celebrated his 69th birthday just a week after he passed away.

I would like to thank all of the wonderful people who contributed to his transplant journey. Especially Dr Puneet Malhotra, Phil's GP, and the staff of Salisbury House Nursing Home, nestled amongst the peaceful surrounds of beautiful Upper Beaconsfield in the Dandenong Ranges, where Phil lived in care for the last twelve months of his life.

Phil went through a lot in 28 years of illness but he is at peace now.

Kind regards,
Marilyn Stephenson



LEWY BODY DEMENTIA (LBD) is a type of progressive dementia that leads to a decline in thinking, reasoning and independent function because of abnormal microscopic deposits that damage brain cells over time.

Lewy Body Dementia is an umbrella term that encompasses two dementias that have similar features and are characterized by abnormal deposits of the protein alpha-synuclein in the brain: dementia with Lewy bodies, and Parkinson's disease dementia.

www.alz.org and Wikipedia

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Proud print partner

 **Finsbury Green**

www.finsbury.com.au

The staff were so welcoming and the location was very convenient to get to the Alfred almost every day.

The financial assistance from the HLTTV after my husband's transplant was so helpful for our stay.

HLTTV Signature Program

HLTTV Second Chance Accommodation Program

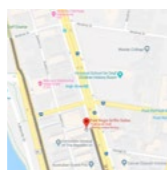
Since May 2012, HLTTV, through our *Second Chance Accommodation Program*, have been thrilled to partner with the *Park Regis Griffin Suites* to provide affordable, accessible and practical accommodation for regional transplant recipients.

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



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.



The HLTTV provides a wide range of support

The Heart and Lung Transplant Trust Victoria (HLTTV) is a 100% volunteer-based, not-for-profit organisation that supports organ recipients and their families and carers in the lead up to, during, and after a heart and/or lung transplant at the Alfred Hospital in Melbourne.

Our services and programs include:

Second Chance Accommodation Program (SCAP)

This key program of the HLTTV provides subsidised accommodation* during the rehabilitation period immediately post-surgery for patients who live in regional and rural Victoria (more than 100km from Melbourne), or interstate.

Donations to The Alfred

The HLTTV periodically make donations to The Alfred to improve facilities for transplant patients including treadmills and other equipment for the Transplant gyms and rehabilitation programs.

Fitness Grants

The HLTTV will reimburse eligible post-transplant members 50% of receipted costs up to a \$150 maximum* to cover the cost of appropriate fitness activities and equipment (eg mats, dumbbells).

Emergency Financial Assistance

The HLTTV provides ad-hoc financial and other assistance, up to a max \$300*, to patients, families and their carers who may be in need of emergency help leading up to and post-surgery.

Heart to Heart Respite House (Barmah, Vic)

Pre and post heart and lung transplant patients and carers can rest, recuperate and recover in this fully self-contained house in a peaceful environment. Just bring clothes and food, your linen (if not hiring) and get set for a relaxing time. Available for up to 6 nights respite.

Information and support about transplants and organ donation

The HLTTV provide a range of resources on our website which detail information about heart and lung transplantation for patients and carers. There are online versions of our quarterly publication 'The Circulator' and information from Donate Life regarding organ donation.

Peer Support

Connecting with other transplant patients either leading up to or post-surgery is an important way to understand and navigate the challenges you will face on your journey. HLTTV can provide information, contact points and assistance for patients wishing to connect.

Social events for members of the heart and lung transplant community

The HLTTV hold a number of social events each year including Easter and Xmas BBQs in Fawkner Park adjacent The Alfred Hospital and a Gala Dinner which acts as a major fundraiser for the Trust. We can also assist members with regional events.

Visit us at www.hlttv.org.au

* Criteria for subsidy or assistance applies, see www.hlttv.org.au for details

TRANSPLANT 2020 ANNIVERSARIES



HEART

FEBRUARY

Mark Brewer, 2008
Margaret Neilson, 2009
Katrina Rehlaender, 1993
John Winter, 1992

MARCH

Gary Down, 2012
Sue Konieczny, 2008
Edward O'Bryan, 1990
Matthew Orchard, 2014
John Prior, 2008
Rod Pulford, 2018

APRIL

Nicole Armstrong, 2014
Ivan Clark, 2015
Graeme Klemm, 2019
Bill Saunders, 2010



HEART + LUNGS

Carla Bondini, 2014
Jose Lopez, 1990



LUNGS

FEBRUARY

Ettore Bastianelli, 2014
Phyllis Cremona, 1994
Ken Gain, 2004
Peter Hohmann, 2016
Kirsten Larsen, 2003
Frank Lineen, 2008
Peter McDonald, 2019
Toni Miles-Bennett, 2011
Robert Smith, 2019
Ronnette Williams, 2015

MARCH

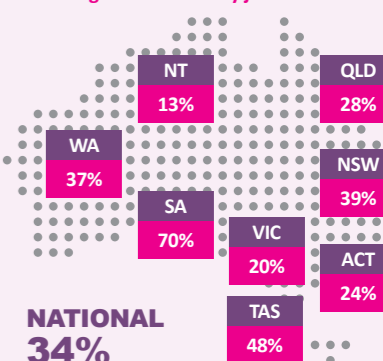
Donna Brayshaw, 2018
Laurie Crowther, 2017
Eric Gethin, 2018
Judi Groves, 2012
Heather Hill, 2006
Anh Nguyen, 2019
Arthur Pape, 2016
Jon Rolfe, 2009
Chetan Shah, 2016
Craig Wood, 2018
Vicki Yfantis-Cocossis, 2013

APRIL

Ann Convey, 2012
Christine Flack, 2014
Sam Ira, 2013
Robert Regan, 2017
Bruce Vernon, 2015
Benjamin Watt, 2017

Donations in Australia

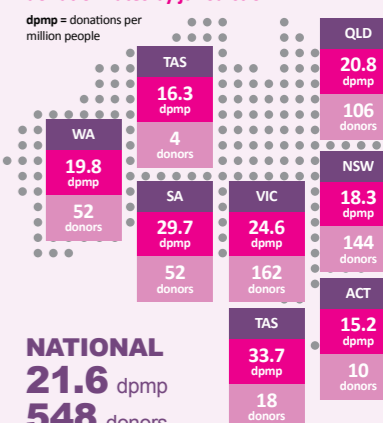
2019 registration rates by jurisdiction



NATIONAL
34%

Note: Clinical practices, demographics and case mix can impact state and territory consent rates.

2019 deceased organ donors and donation rates by jurisdiction



NATIONAL
21.6 dpmp
548 donors

The importance of registration and family discussion



2019 Australian Donation and Transplantation Activity Report

Alfred transplants 2020



Note: these figures are for the period January 1 – March 14, 2020



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

The experience of heart and lung transplantation in Australia

Monty’s heart problems started in the 70s when he had a serious heart attack. He had several heart surgeries in the 80s and, finally, in the 90s was added to the transplant waitlist.

When he received the call asking him to be at the hospital by 8pm, a sense of disbelief washed over Monty. After the surgery, 22 years ago this year, Monty remembers thinking “the wonderful thing is, I can breathe. I was breathing unaided.”

Carole first got sick in 1991. After seeing every specialist under the sun, she was told she had six months left on the Earth. “I thought that was pretty grim,” Carole recalls, wryly. But then she got better. Over the subsequent 20 years or so, the pattern repeated itself. Get sick, get better. But every time Carole got sick, it was worse than the time before. Fast forward to 2012, where on a flight home from Sydney with her granddaughter, Carole thought “this is probably the last flight I’ll take. I felt so ill.” Not long after, her specialist said he could no longer help her, and it was time to head to the Alfred. After two false alarms, in July 2013 Carole finally underwent her lifesaving surgery.

These are just two of the seven captivating and emotional stories from transplant recipients who have shared

AN ONLINE RESOURCE FOR PEOPLE FACING TRANSPLANT

UNIQUE ONLINE RESOURCE
LIVE NOW ON THE HLTV WEBSITE

their transplant journey. Each story is unique, while reflecting the emotional rollercoaster everyone rides on their organ transplantation journey. Fear. Joy. Frustration. Relief. All this and more are captured in these stories.

Sharing stories like these can make it a little easier for the next person starting their own journey. Which is why Dr Claire Stubber PhD and Dr Maggie Kirkman PhD at Monash University’s School of Public Health and Preventive Medicine started this research project to learn about how people experience heart and lung transplantation.

Everyone interviewed understands how hard it is to know what to expect when you or someone you love is told that they need a new heart or lungs. They also wanted to inform the medical and other staff who deal with them.

The resource is particularly useful because the videos have been segmented into 20 topics such as *Life before transplant*; *Making the decision*; *Waiting*; *False alarms*; *The call*; *Waking up after surgery*; and *Life after transplant*.



Dr Claire Stubber

Claire is an Adjunct Research Fellow at Monash University. In addition to her scholarly qualifications, Claire has the experience of having lived for more than 20 years with transplanted heart and lungs; she tells her story as part of the resource. Claire is a past committee member of the Heart and Lung Transplant Trust (Victoria). Claire’s PhD examined both the experience of heart and lung transplantation and Mary Shelley’s novel *Frankenstein*. Claire carried out the enormous task of segmenting all the videos into the 20 topics.



Dr Maggie Kirkman

Maggie is a Senior Research Fellow at Monash University and a member of the Australian Psychological Society. Her research focuses on psychosocial aspects of health, bodies, reproduction, and sexuality. She has expertise in qualitative research methods, especially the use of in-depth interviews for investigating sensitive topics. Her research has been published in international peer-reviewed journals as well as disseminated in books, chapters, and articles for the general reader. Maggie is the interviewer in these videos.

Visitors to the site can choose to watch a person’s whole video or select short clips about a particular topic.

Claire and Maggie hope to be able to expand the resource to include more people. There’s also a link to a short evaluation survey on the site so you can let us know what you think of the videos.

The Monash University researchers work in partnership with the charity *Heart and Lung Transplant Trust (Victoria)* and the *Alfred Hospital Lung Transplant Service*.

This project was made possible by a grant from the Grenet Foundation courtesy of Ann Hyams and by in-kind support from Ian Stubber, who organised and set up the video equipment.

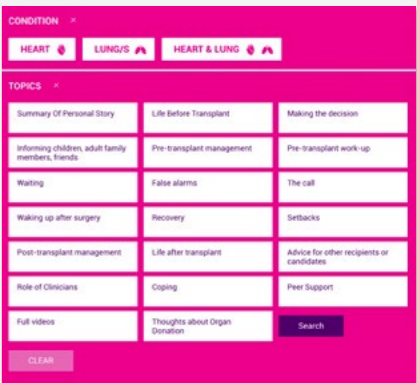


Using the resource

Once you have navigated to the resource on the HLTV website, you can read a short biography about each recipient:



and then either watch someone’s entire interview OR simply search through a range of topics that may interest you.



There’s always something comforting hearing from others who have already been through the experience.

BERNIE

7 Years Post - Transplant

HEART TRANSPLANT

READ MORE

MONTY

22 Years Post - Transplant

HEART TRANSPLANT

READ MORE

CLAIRE

19 Years Post - Transplant

HEART & DOUBLE LUNG TRANSPLANT

READ MORE

CAROLE

2 Years Post - Transplant

SINGLE LUNG TRANSPLANT

READ MORE

CAMILLE

2 Years Post - Transplant

DOUBLE LUNG TRANSPLANT

READ MORE

STEPHEN

3 Years Post - Transplant

DOUBLE LUNG TRANSPLANT

READ MORE

LOUISA

5 Years Post - Transplant

DOUBLE LUNG TRANSPLANT

READ MORE

Front cover photograph kindly provided by Thach Tran, one of Claire and Maggie’s colleagues.

Routine & Commitment

Post-transplant routines and your commitment to them are key to a successful transition from a normal to a ‘new’ normal life ahead of you

Routinely taking the range of anti-rejection and associated medications are one of the important ways in which transplant recipients can maintain a successful trajectory.

After your surgery, you will need to take medications (also called immunosuppressants) to keep your body from rejecting the new organ. Once taken, they stay in your blood for a certain period of time. To protect your organ, the amount of medication in your blood must be maintained at appropriate levels.

Your transplant team will instruct you on how to take your immunosuppressants, and adjust the doses so that optimum levels of the medicines are absorbed in the blood. You must take the medicines every day at the same time to ensure these levels are maintained.

Missing even a single dose or stopping the medicines without guidance from your doctor can put your organ at risk.

The amount of medications may reduce over time, but you will have to take them for the rest of the life of your transplant.

It can be tricky to keep to a routine with your medicines. Recipients sometimes find it difficult to remember the right doses, the combination of pills prescribed, and to take them at the same time every day.

To stay on track easily, familiarise yourself with the following:

-  **Name of each medication**
-  **When to take each medication**
-  **How to take each medication**
-  **Why each medication is needed**
-  **Major side effects of each medication**
-  **Food or drugs to avoid with your medication**
-  **Actions to take if you miss a dose**
-  **How and when to refill the medications**

Courtesy Transplant Australia



Tips for managing medications

It is advisable to have drugs organised in a pill box. Setting up a pill box will help you get familiar with your medication and the doses.

Ensure you have adequate repeats on your scripts when you visit your transplant doctor. Plan well in advance to replenish your supply so you don't run out.

Start making a habit of taking the medicines at the advised times as soon as possible. Some recipients set alarms on their watches and phones as reminders to help them keep to a routine.

Keeping a list of the pills you take, along with the doses, in your wallet or bag can be handy. Remember to update the list each time the doses change.

IMPORTANT

If you've had challenges sourcing medications at your local pharmacy or even about the process please email about your experience to *The Circulator* so we can try and assist.

circulator@hlttv.org.au

Join 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 email her on larna.kennedy@bhs.org.au



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

Hearts and lungs transplanted nationally from deceased donors

In 2019, there were 1,501 total organs transplanted from deceased donors, 7% lower than 2018. Heart and lung transplantations were reflective of this slight decrease.



113
129



183
222

2019 2018

2019 AUSTRALIAN DONATION AND TRANSPLANTATION ACTIVITY REPORT
AUSTRALIA AND NEW ZEALAND ORGAN DONATION REGISTRY

2018 AUSTRALIAN DONATION AND TRANSPLANTATION ACTIVITY REPORT

Potential to improve is quite significant

Donation is an infrequent event. Only 2-3% of people who die in hospital can become an organ donor as particular circumstances need to occur for a patient to be medically suitable to donate.

By way of example, in 2018, of 78,525 deaths that occurred in hospitals, approximately 1,211 potential donors were identified. Requests to families for donation were made in around 1,118 cases, with 716 families consenting to donation. Of those, in 162 cases donation did not proceed for a variety of clinical reasons.

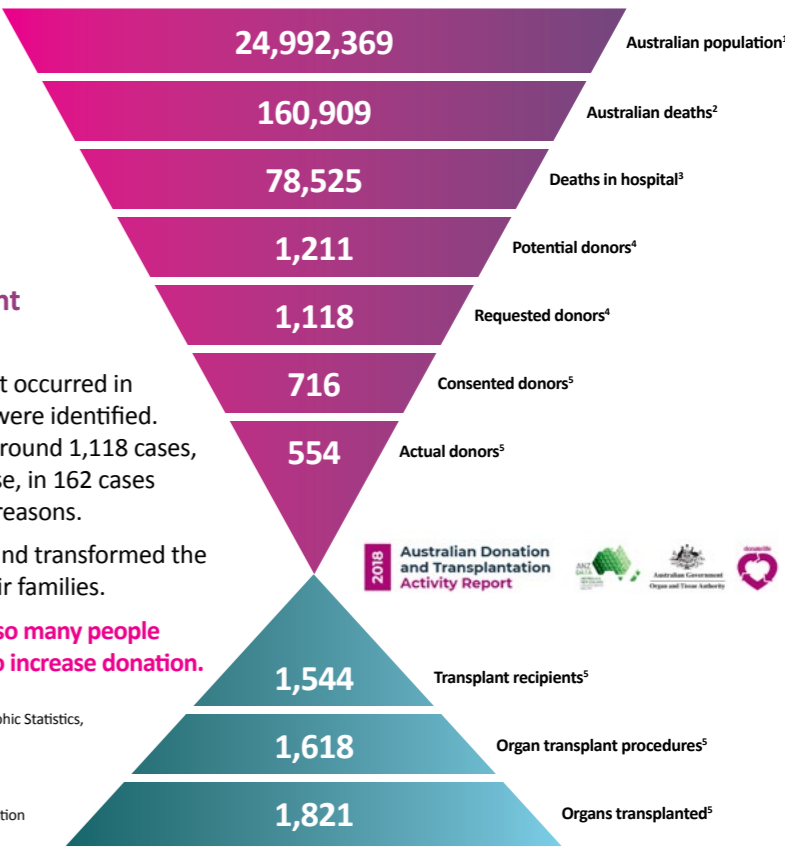
The resulting 554 deceased organ donors saved and transformed the lives of 1,544 organ transplant recipients and their families.

With donation possible in so few cases, and with so many people needing a transplant, it is vital that we continue to increase donation.

Source

- 1 Estimated Resident Population 30 June 2018, ABS 3101.0 Australian Demographic Statistics, (released 20 December 2018)
- 2 ABS 3302.0 Deaths, Australia, 2017 (released 26 September 2018)
- 3 AIHW Australian Hospital Statistics 2015-17 (released 24 May 2018)
- 4 Estimated using DonateLife Audit Data (February 2019)
- 5 Deceased Organ Donation in Australia, Australia and New Zealand Organ Donation Registry, January 2019

Deceased organ donation and transplant recipients 2018



2018 Australian Donation and Transplantation Activity Report





Scott and wife Sue in Japan post-transplant celebrating a world full of possibilities

Back to Balance

The transplant journey is remarkable. One that is by no means over as you climb past the first few weeks and months of intense recovery.

I am approaching 18 months post heart transplant and thought I might share what the medium term journey has been like for my family, friends and me.

I was transplanted in late 2018, after spending nine months with two Ventricular Assist Devices (VADs) – it was a journey full of ups and downs (more ups than downs) and thanks to the Alfred team, my wife and my family and our friends – I am here to share the next part of the story.

I am sure most post-transplant recipients and families would remember what those first few weeks and months are like at home – you are still attending gym, getting used to the new medications, going through the routine biopsies and dealing with the peaks, dips and bumps as things settle down.

By Scott Moorhen

In my case I am happy to say I progressed pretty well through that phase; the Biopsies became less and less frequent and then stopped; the medication regime settled down and a normal rhythm of living returned.

After the intense interactions, this transition almost feels like being launched into space – the team and everyone is still there to support but I felt very much that I was standing on my own – which is both exhilarating and a little scary.

The boundaries to activities continued to move out as I got physically stronger and mentally more confident. I have become involved in a range of things including photography and race tech for Whitewater Canoe Slalom (more shortly) and teaching light and sound

engineering as a co-curricular activity at my children's high school.

The Kayaking has taken the family to Western Tasmania (the Mersey River), Eildon (near Melbourne) and the Penrith Whitewater course – built for the Sydney Olympics. Kate, my youngest, is well and truly hooked on this sport.

As the transplant recipient it has taken months to tease apart my own journey from my wife, Sue's, perspective. We have been a strong team through this experience but I am increasingly learning that a lot happened at the time of the VAD implantation and the subsequent transplant that, given my own state of sedation etc, I was not aware of but that the family lived through in real time.

From my perspective I have only gradually felt comfortable to unpack



Scott's youngest daughter Kate, along with the rest of his close family, has been an inspiration on his transplant journey

this part of the story over time. For me it is about taking life experiences on board fully more completely understanding how Sue and the family were affected by what was happening. They are at times confronting discussions – and maybe not for everyone – but I have found it a key aspect of my recovery and journey back to my new normality.

Getting back together with friends and meeting new people, I find myself now kind of as “two stories” in one. There are those that know me from my past life, before I became ill – based around

a corporate career working in the Mobile Communications industry for 25 years. I worked on (amongst other things) Network Operations and new feature development and upgrades.

Then there are those that now know me as “the transplant guy”.

For those that don't know the specifics of what the transplant journey involves it is almost beyond comprehension and difficult to grasp. I find I am now much more conscious of how people are going absorbing the story and adjusting accordingly.

By now, the medication routines are part of very routine daily life including checking supplies and scripts. Likewise on the food front – we are appropriately cautious but not overly paranoid about food and food poisoning – the approach post immuno-suppressants has not dramatically impacted my eating habits with the exception of, in particular, edgy dairy products and shellfish. I am enjoying using our local gym, rightly or wrongly I was never a big swimmer or spa user – so thankfully that has not been a big issue for me.

We like travelling – within Australia and overseas – we have just done our first post-transplant trip overseas to Japan which went very well in terms of medication logistics and food – it was a great and very liberating experience.

Everyone's path is different – for me the transplant has been a gift that keeps giving in terms of new experiences and learnings on many levels. It has taken some time to approach a new “normal”, feeling out where boundaries remain and becoming at ease with life before and after the transplant – I have found in my case patience and persistence pays off handsomely.

Best wishes to all on your journeys.

Our new members

The HLTTV Committee welcomes our new members.

We are a 100% volunteer-based, not-for-profit organisation that supports organ recipients and their families and carers in the lead up to, during, and after a heart and/or lung transplant at The Alfred.

Pre-transplant
Barry Katzenberg

Carer
Trevor Barrett, Peter Blackshaw

Heart
Colin Cairnes, Sam Di Natale, Paul Grassick, Stephen Patching

Heart/Lung
Daniel Harwood

Lungs
Josie Barrett, Michele Cassidy, Annie Greig, Jessica Luxford, Anh Nguyen, Giulia Papa, Nadina Saifert, Robert Smith, Craig Wood

MOVE MORE THIS APRIL

PREMIER'S ACTIVE APRIL

NEW IN 2020 – SYNC YOUR FITBIT TO THE ACTIVE APRIL APP

The all-new Fitbit app makes it even easier to track your activity during April. Register now to win great prizes that will help you move more!

As part of the Victorian Government's commitment to promote healthy, active lifestyles and get Victorians to join in the fun of increased physical activity, **Premier's Active April** is back in Melbourne and bigger than ever for 2020 – **Registrations are now open and it's time to jump on board again.** It's free, it's fun and it's promoting all Victorians to do just 30 minutes of physical activity a day to keep you healthy.

SPORT AND RECREATION VICTORIA
Department of Jobs, Precincts and Regions
80 Lonsdale Street, Melbourne VIC 3000
GPO Box 4807, Melbourne VIC 3001
W: active.vic.gov.au | E: active@sport.vic.gov.au

Authorised by the Victorian Government | Treasury Place, Melbourne

The Gippsland Model Engineering Society's generosity is anything but miniature!

On behalf of lung transplant recipient Josie Barrett, the Traralgon Miniature Train Club has donated \$800, half of which will go to HLTTV and the other half to Lungitude.



Josie Barrett enjoying a spin on the train



Paying it forward

Heart-transplant recipient Petra Brosch is determined to make her second chance count!

I had the privilege to volunteer for the Disabled Surfers Association Bass Coast on Saturday, 15 February at Inverloch Beach.

This was a very special event for me, as surfing has played a major role in my recovery before and after transplant. In ICU, whenever I was on the brink of “I can’t take it anymore, just let me go” I went back to my happy place, in the ocean, the blue water, smelling the fresh sea breeze, touching the cold water and seeing myself catching a wave.

It was a really powerful tool to keep me motivated and positive, and if you would see me today, you would never think that I was dead for 20 minutes, spent 4 weeks in a coma and had a heart-transplant.



The ocean is a beautiful thing, it doesn’t judge, it welcomes everyone the same.

Having made a full recovery, I want to spread that power, that joy, to others who are less fortunate than me, and can’t go to the beach by themselves, let alone surf.

Once at the beach, we were divided into volunteers on land, and on water.

I took on the water of course.

We were divided up in 4 groups of volunteers and had a few dry runs, practicing lifting people out of the wheelchair, and shifting them onto the surfboard. We would then lift up the surfboard with the participant on top and carry them into the water. Once in position, one person would always join the surfer at the back of the board, securing them, and helping to steer if needed during the ride.

Every surfer got a minimum of 5 rides.

We had all sorts of people: kids, adults and all classes of disability.

For this one day, surfers were experiencing the ocean like everybody else. For one day, they could feel without a disability holding them back. To see that excitement in people’s eyes was amazing.

The ocean is a beautiful thing, it doesn’t judge, it welcomes everyone the same.

It is an experience that will stay with me for a long time, and that I will repeat again.

If you want to know more or join me, please visit www.disabledsurfers.org

Petra Brosch, 37, underwent a heart-transplant in 2018. She now lives her life with a profound sense of purpose to make sure others share in her joy.

Your membership counts



PERSONAL DETAILS

Name	Partner’s name (if applicable)
Address	Postcode
Postal address	Postcode
Telephone	Mobile
Email	Date of birth

NEW MEMBER

I wish to become a member of the Trust ☐

EXISTING MEMBER

I wish to renew my membership ☐

CIRCULATOR NEWSLETTER

I wish my copy to be emailed ☐

I wish my copy to be posted ☐

MEMBERSHIP TYPE 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)

OR **CARER** | **SUPPORTER** | **OTHER** (please specify)

Signature _____ Date _____

Membership for Pre-transplant members is free. An annual donation of \$15 applies to all other categories of membership.

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 additional donations. Donations over \$2 are tax deductible.

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



Members may also join online and pay membership and donations via direct debit bank transfer. Please visit <http://www.hlppv.org.au> and follow the ‘Membership’ links.

Protect yourself and your family

Wash your hands regularly

Key prevention measures against coronavirus (COVID-19)



1

Wet your hands.



2

Put soap on your hands.



3

Rub the soap over all parts of your hands for at least 20 seconds.



4

Rinse your hands under running water.



5

Dry your hands thoroughly with disposable paper towel or hand dryer.

Stay germ free and healthy

Protect yourself and your family

Cover your cough and sneeze

Key prevention measures against coronavirus (COVID-19)



1

COVER your mouth and nose with a tissue when you cough or sneeze.



2

Put your used tissue in the rubbish **BIN**.



3

If you don't have a tissue, cough or sneeze into your upper sleeve or elbow, **NOT YOUR HANDS**.



4

WASH your hands with soap and running water. Dry your hands thoroughly with a disposable paper towel or hand dryer.

Stay germ free and healthy