The Circulator

Heart & Lung Transplant Trust of Victoria Magazine | Edition 106 | 2025



Some families experience one transplant journey. Very few experience three of them.

"I am surrounded by heroes—each shaping my family's story with courage, sacrifice and love—and I carry pride and awe for the hearts that walk this journey with me." ANGELA CAIRNS | PAGE 8

HLT TV
HEART & LUNG TRANSPLANT TRUST VICTORIA



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Established 1994

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 or Ventricular Assist Device (VAD) implantation at the Alfred Hospital in Melbourne.

Our Vision is for a bright and active future for all those involved with or in need of a heart or lung transplant. We actively encourage organ donation and support The Alfred Hospital Melbourne, the Transplant Team, patients, recipients, their families and carers throughout their journey.

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Enquiries If you would like to make a contribution to *The Circulator* please contact Graeme Klemm on 0421 327 096 or email graeme.klemm@outlook.com.au

Cover image: The Cairns family together, thankful and appreciating the incredible reality of facing down multiple transplants within their family (Left to right: Lucas, Angela, Luka-Angel, Jazz, Jai and Elijah).

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President's message

A legacy of support: Over 30 years of care for heart and/or lung transplant recipients



The HLTTV was founded in 1994, just five years after the heart and lung transplant service commenced at The Alfred.

For over three decades now, the HLTTV has been dedicated to supporting transplant recipients and their families. Though small in size and entirely volunteer-run, the HLTTV has consistently made a difference in the lives of heart and lung transplant families.

Our most valuable assets are our members and supporters, who work so hard to provide essential support and care to the transplant community. We currently have about 150 members in the HLTTV.

Our thanks to James Ure and Wanda Moyle for all the work they have done in maintaining and updating the membership database.

Our key initiative is the Second Chance Accommodation Program (SCAP), which provides accommodation support for heart and lung recipients who live more than 100 kilometres from The Alfred. Since its launch in 2012, SCAP has been a lifeline for heart and lung transplant families facing some of the toughest moments of their lives. In 2024, we partnered with Rockmans Apartments as our new accommodation provider.

We are deeply grateful to Robert Rockman and his team for the care and support they have shown the transplant community. But unfortunately SCAP costs money. HLTTV supplies $750 per room, per month to keep SCAP running. In 2024 we faced a hard decision – we had to reduce the number of rooms we fund from four rooms to three. This means that there is one less family each month who can access safe accommodation close to The Alfred, at a critical time in their recovery.

Securing funding for SCAP and our other HLTTV programs continues to be a challenge. In 2024-2025, we recorded a small overall loss of $1,826, thanks to all of YOU our generous members and supporters.

Our most successful fundraiser was our walk around Fawkner Park in December 2024, which raised over $12,000. There was a large contingent of people walking to honour the memory of our dear friend and long-time committee member, Maarit Moilanen, as well as many other HLTTV members and friends.

We're also grateful for generous philanthropic contributions, including $1,000 from the Grant Family Trust as well as from the Caretta Mason Trust, which pledged $5,000 annually from 2023-2026.

The Rotary Club of Torquay continues to support us with $2,000 per year and we celebrate the inspiring efforts of individual fundraisers like Jennifer Pope and Daniel Braines.

To all our donors – thank you. We wouldn't be able to do our work for the heart and lung transplant community without your support.

We are excited to share developments regarding the Heart-to-Heart (H2H) respite house in Barmah. For more



Tessa Keegel, Tracy King and Petra Brosch at the Parliament Friends of Transplant Australia event as part of DonateLife week.

information please have a look at James Ure's Secretary report.

We look forward to continuing the close relationship between the HLTTV and the H2H House and enjoying relaxing times in Barmah.

Special thanks to the HLTTV Committee, especially Vice-president Martina McArdle, Secretary James Ure, Treasurer Sue Laksassi, Membership Officer Wanda Moyle, Graeme Klemm for all his work on The Circulator, as well as our other committee members Sam Ira, Petra Brosch, Claude Turco, Trudi Jones, Gaylynn Pinniger, Sam Osbourne and Tracy King.

We are excited to welcome a new committee member for 2025, Angelo Alateras, who was responsible for our wonderful mid-winter event at the Oakleigh Bowls Club celebrating his heart transplant journey.

We encourage anyone else interested in joining the HLTTV committee to contact us at president@hlttv.org.au.

As always, we honour the generosity of all our organ donors as well as the selflessness of their families. They donated their organs so that we might have a second chance at life. These donor heroes continue to inspire our work, and the efforts of the HLTTV are a tribute to their legacy.

We also remember and honour the members of our transplant community who have passed away in 2025.

We have exciting plans for 2026, including fresh fundraising strategies for SCAP.

Our vision at HLTTV is for a bright and active future for all those involved with or in need of a heart or lung transplant.

In 2025, we have made leaps and bounds towards this goal. Thank you all for your support. we look forward to seeing you at the 2025 end of year BBQ on Sunday November 23rd at 11.00 in Fawkner Park.

Here's to another year of making a difference together at the HLTTV.

Tessa Keegel
President

2026 HLTTV Committee



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Angelo Alateras

The HLTTV welcome any members of the community who would like to make a volunteer contribution to assist and support people on their heart or lung transplant journey, particularly raising funds for our Second Chance Accommodation Program (see page XX)

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HLTTV

Secretary's notes

Building community, supporting transplants recipients and encouraging organ donation is our mission.



Hello. As the current Secretary of the Heart & Lung Transplant Trust of Victoria (HLTTV) I'm pleased to be updating you again on some HLTTV news and events, and providing our community with a few reminders of how you can participate with HLTTV.

The HLTTV Committee is strongly committed to delivering the HLTTV vision for a bright and active future for all those involved with, or in need of, a heart or lung transplant.

We actively encourage organ donation and support The Alfred Hospital Melbourne, the transplant team, patients, recipients, their families and carers throughout their journey.

Although we are a small and entirely volunteer group, we know that HLTTV is in a unique and privileged position to understand the transplant journey and make a difference to our community. We strive to do this through our support programs, by fostering a sense of community within the transplant community through communication and providing opportunities for social engagement, and by providing resources for support, education and advocacy.

Heart to Heart Respite House

An important development in 2025 for HLTTV has been the assumption of responsibilities for the all of the management and running of the H2H Respite House in Barmah, albeit under a separate but closely related organisational structure.

Sadly, the Nathalia Rotary Club, which had for many years supported this respite facility, and provided the Committee which undertook overall management of the facility, was disbanded in late 2024.

In disbanding, the Nathalia Rotary Club requested that HLTTV take over the respite house and all of the responsibilities associated with the house.

Consequently, members of the HLTTV Committee now also from the backbone of the H2H Respite House Inc committee of management.

This new arrangement has provided some impetus in renewing aspects of the respite facility – a new on-line booking system is now available for use in booking the house, and its availability for respite broadened to include the full range of transplant recipients, their families and carers.

We would encourage you to consider using our wonderful respite house. It is relaxing and low-cost accommodation in a great, peaceful location. Full details are available at the H2H Respite House webpage (see QR code and information on the facing page).

And look our for our bright new brochure...



Our wonderful members

Having a strong membership base is important to HLTTV and allows us to continue to support the broader transplant community.

Membership of HLTTV aligns with each financial year from 1 July to 30 June of the following year.



Thus, renewal of HLTTV membership for the 25/26 year became due again on 1 July 2025.

Cost of HLTTV membership is just $20 per year. If you have not yet renewed your membership please consider doing so.

You can renew your membership by directly depositing your $20 into the HLTTV Bank Account.

The HLTTV Banking Details for making your direct debit deposit are:

Account name: Heart & Lung Transplant Trust (Victoria) Inc
BSB: 033002
Account No: 415-147

Please remember to include your name(s) with the details in the reference field when you make your membership payment so we can keep up to date with membership payments.

If you wish to make an additional donation to HLTTV when paying your membership, this would also be gratefully received. Any donations received in addition to membership monies, will be recognised as such, and a receipt will be forwarded to you via email so that you can claim your donation as a tax deduction for the 25-26 FY.

Finally, I would recommend that if you have some time to assist us, please consider joining the HLTTV Committee to assist us in the work we do. I can attest to the satisfaction to be gained from participating on the HLTTV Committee – we always have more things to work on than we do resources and people. It would be great to have additional committee members to support our goals in 2026.

Our hardworking and dedicated President, Tessa Keegel, would be more than happy to talk to you about these opportunities. You can reach out to her on **president@hlttv.org.au**

As Secretary, I am always happy to receive correspondence about suggestions thoughts, changes to postal/email addresses and even complaints.

Please send through to me at secretary@hlttv.org.au

All the best,
James Ure



Heart to Heart Respite House
26 Schier Street, Barmah VIC 3639

BOOKINGS:
www.hearttohearthousebarmah.com
Phone Martina: 0468 193 277

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The gift of life and the strength of family: the Cairns family transplant journey



I am surrounded by heroes

I am surrounded by heroes—each shaping my family's story with courage, sacrifice and love—and I carry pride and awe for the hearts that walk this journey with me.

By Angela Cairns

I have come to realise there are many heroes in every transplant story. From doctors, to surgeons, to donor families, to transplant coordinators, nurses, organ retrieval specialists, to family and friends who fervently pray and support, to parents or carers who fight to advocate for their loved one.

Then there are the hero siblings of young recipients who watch on helplessly, facing many times when their parents attention has shifted, or their world is turned upside down.

I am surrounded by heroes, of that I have no doubt, and feel a mix of pride and awe when I consider the courage of my family. Our circumstances have driven us to love more, live big, persevere on dark days, remain grateful for small things, pursue quality time, make time for adventures, forgive quickly and live with purpose! It means the petty little things don't matter so much nor the desire to 'have', gain or strive for worldly pursuits. Our hearts have lived a roller coaster of highs and lows. We continue to hold life with careful reverence, comprehending the importance of intentionality in how we approach it. I'm pretty sure I live with the most courageous hearts in the world, including my eldest and youngest sons, who have bravely fought these battles too.

I have watched both the suffering and triumphs of my kids and husband over many years. Some moments I still unfold in tears, but mostly, I feel a sense of gratitude that they are mine, and they are still here. It is hope and faith that drives us forward each day, and I can reflect that approaching life one day at a time sustains me.



Our family embraces every day with passion and purpose

L to R: Lucas, Luka-Angel, Jazz, Elijah and Angela

Right: Suporting Lucas after his transplant



A time to dance

A time to dance was once only a dream, but my gift of a new heart turned restriction into freedom and gave me the chance to live the rhythm I had always longed for.

By Luka-Angel Cairns | Heart transplant

The anticipation rises from my stomach to my head as I stand in the darkness of the wings waiting eagerly to hear the first hum of my song. When it starts, all nerves somehow disappear as muscle memory kicks in.

I don't need to remember the dance routines; my body seems to do it for me. This feeling is like no other, as I allow my body to move, whether it's to the choreography I've practised all year, or the freedom of improvisation.

There is no denying I feel most at home when I dance.

As a little girl my greatest desire was to be a dancer. I didn't need to be the prima, the soloist, the professional. I just needed to be part of a dance class.

For most little girls, being in a dance class wasn't an unusual thing, but for me, my failing heart disconnected that dream and my reality.

At six, I was diagnosed with a one in a million condition, Restrictive Cardiomyopathy... a fitting title really. Restriction was certainly a big part of my condition. Growing up, I had to avoid physical exertion, school sport, staircases, long walks and dance.

I always understood that heart transplant was my only option for life. Although not a cure, it was a treatment I not only needed to survive but desperately wanted. I was sick of the restriction on my life.

When I was thirteen, I received my gift. Laying on the operating table before being put into a deep sleep. Mum asked me what type of dancing I wanted to do when I was better, and so I listed off all the different dance classes I would do until I fell 'asleep'. Little did I know, things wouldn't go well. My new heart didn't start... I was kept alive by machines (placed on ECMO).



Living my dancing dream

Opposite: Angela with Luka-Angel in ICU

After 13 days of many prayers, waiting, resuscitation, incredible miracles, extra surgeries and hard-working medical professionals I gained complete heart function (though I continue to live with a pacemaker to support the electrics of my heart).

Of course, transplant was a long, difficult road and some days I felt like dancing was still a lifetime away. A gifted pair of second-hand Pointe shoes hung at the end of my bed in hospital, to remind me of my goals.

My new heart, although a rocky start, was and is my greatest gift. Each morning I wake up, grateful to my donor and the life she gave me.

Now, at 22, celebrating 9 years with my new heart, I have been dancing almost 9 years. I have done beyond the amount of dancing I could ever have dreamed of. I've had years of dancing in my very own pointe shoes, performing and even teaching and choreographing for my own classes with the dance studio that has been my home for 8 years.

Organ donation not only saved my life, but it made my greatest dream a reality.


CPAP / PRV
0.24
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18
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9

Finally free

Finally free, my journey has carried me from loss to new life, where faith and resilience lifted me from isolation into the freedom of a heart restored.

By Jazz Cairns | Heart transplant

I was ten years old when my sister Luka went through her transplant and it was pretty traumatic so I don't remember much. I just remember losing my 'best friend' for a bit (and missing her). We had been through so many medical things together for years, and now she was doing it by herself.

I was thirteen years old when my time came for a heart transplant (four years after my sister's).

The day my call came was so unexpected. It felt so rushed as I was given 15 minutes to leave school, go home and drive 3 hours to the airport in Sydney. My transplant was in Melbourne at the Royal Children's Hospital.

When I got to the hospital that night, I remember feeling like I was floating, watching everything happen around me, as if I was outside of my body. I didn't feel very nervous. I mostly felt at peace. I felt like God was protecting me.

When I got into theatre, I noticed the hardness of the operating table underneath me – for some reason I had thought it would be soft.

I was only at the hospital for less than half an hour, before I said goodbye to my older brother, sister and Mum who were allowed to come with me. Dad walked into theatre with me until they put me to sleep.

My memories of ICU are like flashes. I was conscious and aware at times. Mum recalls I wrote a lot of messages



when intubated including asking people to pray for me. My Mum and Dad barely left me and many people were praying for me.

Being in ICU was uncomfortable with all the machines I was hooked up to and the inability to move properly.

In the ward when I started to come around there were times I was in a lot of pain and discomfort. Even my hair had formed dreadlocks over my time in ICU and it took a long time for Mum to brush them out - everything hurt – even my scalp. I also had a lot of migraines.

Noone could visit me when I was in hospital due to Covid restrictions. A few years before I had been at the same hospital for my sister's transplant but we were surrounded by family and friends. This felt so different and it was a time of huge restrictions.

Luka-Angel says of going through her brother, Jazz's transplant 4 years after her own:

"I really struggled that due to covid restrictions, I couldn't see my little brother in hospital over his transplant. It was so hard because we had always done our medical journey together. I always imagined myself being by his side through it. When he got out of hospital, I was so excited to meet him and push him in his wheelchair back to our unit across the road.

I was also excited for the life he'd get to live now he had a new heart. Suddenly we could do so many more things together!"

I felt isolated and far away from home and didn't like that I was getting behind at school, as I had always had good results. The truth is, I never really caught up on the work I missed that year of Covid and two family transplants.

I have always loved sport, but before my transplant wasn't able to do it properly because of my Restrictive Cardiomyopathy which put me at risk of cardiac arrest every day. After my transplant, I couldn't wait to get home and be able to do sport at school. I had always missed out. So I pushed hard in Physiotherapy, wanting to get as fit and healthy as quick as possible now that I finally had a good heart.

It was the day of my fourteenth birthday when I was finally cleared to leave Melbourne and cross the border to go home to NSW. It was a time of strict covid rules and the borders were shut. It felt like we were V.I.Ps when we drove to the border.

The policewoman even had our names written on her hand to let us through. There was barely another car on the road on our long drive from Melbourne to home.



Jazz taking steps to recovery post transplant

Left: Angela and Lucas with Jazz in ICU

Article continues on following page...



Dad's transplant was 4 months after mine (but at St Vincents Hospital in Sydney).

It was so difficult seeing him go through what I had. His recovery was very complicated and we didn't know if he would make it sometimes.

His transplant was also away from home and it was hard to be away from my normal life yet again.

I remember one day we needed biopsies on the same day. Mum was at Westmead Hospital with me, while Dad had his at St Vincents. We saw each other the next day with our matching bandaids on our neck.

The first eighteen months of my recovery was difficult, strenuous and complicated. It was filled with loads of hospital visits (12 admissions in 14 months). I had many issues from immune suppression related to diabetes to colitis to Cdiff to CMV activation, to anemia, adrenal insufficiency and my body struggled to beat viruses and infections.

On some of these days I felt like I would never recover.

When I was finally able to come off steroids, my diabetes disappeared and I no longer had adrenal insufficiency.

This was the turning point when I was finally free do normal things!

I'm now five years post-transplant, am full time at University (first year), playing A-grade volleyball and go to the beach most days with my friends or girlfriend.

Since my transplant I have gone to the World Transplant Games in Perth and equaled the World Record for Under 18's (got a few Gold Medals), completed my HSC, competed in two Sparton Races (obstacle course with 20 obstacles) with Transplant Australia and recently climbed a mountain in the Warrumbungal Range with my best mates (16km return climb). I am the healthiest and fittest I have ever been in my life and love working out with my older brother.

I've had a great transplant/cardiac team in two hospitals (different States) and even got to run in the recent Sparton Race (in the Transplant Australia wave) side by side with one of my transplant doctors.

When I think about what my family have been through, I feel so proud of them for the hardship they have overcome and so thankful for our donors for giving us the gift of life.

I have relied heavily on my faith in God to be my strength and peace. Having a strong family and being supported by so many people through our hard times has helped me persevere.

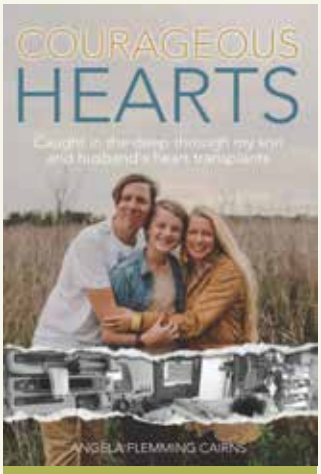
I am also thankful for my closest friends who have always been there for me.

Above left: Jazz with Luka-Angel before her diagnosis

Jazz and Luka-Angel living their dreams



Living proof: Stories of faith, family and the gift of life



Angela's Journey through Lucas and Jazz's transplant.

'Courageous Hearts: Caught in the deep through my son and husbands heart transplants'.

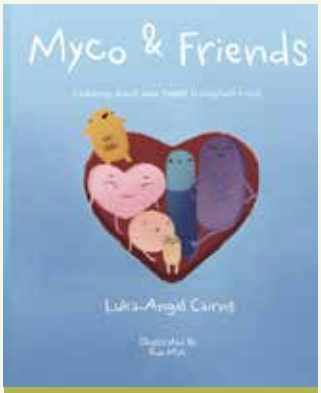
by Angela Cairns



Angela's journey through Luka-Angel's transplant.

'Rainbows in the Storm: Journey Through My Daughter's Heart Transplant'.

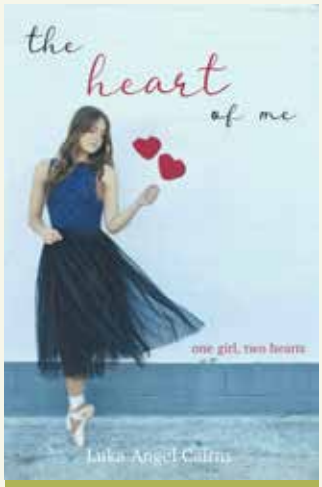
by Angela Cairns



Learning About Heart Transplant Meds.

'Myco & Friends: Learning About Your Heart Transplant Meds'.

by Luka-Angel Cairns



Autobiography.

'The Heart of Me: One Girl, Two Hearts'.

by Luka-Angel Cairns

All our family have a hope that somehow, the sharing of our stories may be helpful and provide encouragement to others who also face the challenges of transplant life. Angela Cairns

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Article continues on following page...

A purposeful life

A purposeful life has taken me from watching my father's second chance to walking my own transplant journey with my children, carried by faith and resilience.

By Lucas Cairns | Heart transplant

One of my earliest recollections is waking up and Dad was gone. Mum explained he had been taken to hospital overnight. I was seven years old.

As I grew, I would come to understand just how unwell my Dad was, though he hid it very well.

In the lead up to his listing for transplant in 1994, he became frail and less able to do simple daily tasks. Yet he remained positive and stoic. He never made his health the focus, always choosing to focus on the positives in life, encouraging his three kids to do the same. He only had months, possibly even weeks, left to live when his call came for his heart transplant.



Back then they would carry a pager around. He was 43 years old and working full time for The Salvation Army as an officer. He lived a purposeful life with his main passion: sharing his faith in action through supporting the community around him. He was a selfless man.

I accompanied him, Mum and a family friend to hospital when his pager went



Angela with Lucas in ICU

Below left: Lucas with his dad

off and refused to go home. I was fifteen years old. The next day, after his successful transplant, we were led down a long hallway and only allowed to peer at him through a glass window to the ICU room where he lay.

The change in his life after transplant was incredible and he lived twenty extra years.

It was about a year and a half after Dad's transplant when my sudden diagnosis came. I was 17years old, in year 12 and it hit me hard. I too, had Hypertrophic Cardiomyopathy.

Dad would always tell me I probably wouldn't need a transplant as technology was constantly changing. I am not sure if this was his way of protecting me, or if he really believed it.

Over the years my symptoms worsened, however, I continued to live my life to the full getting married, having four kids and pursuing, in my Father's footsteps, a music career followed by ministry in The Salvation Army.

I could never have imagined that our two middle children would have a variation of the family condition that would mean they needed paediatric transplants. It was absolutely devastating, and I still live with that guilt today.

It never ceases to amaze me how resilient all my kids are. Even with the challenges faced I see how they love to get the most out of life.

The strength Luka-Angel and Jazz showed me over their own transplant journey inspired me with my own transplant which took place just 4 ½ months after Jazz's – in a different



Angela with Lucas climbing Ben Lomond, New Zealand

State to his. It was also a time of harsh covid restrictions which compounded its difficulty.

By the time I was listed, I probably found it hard to see how unwell I was as this was a life-long condition. It was my normal. When my cardiologist told me I could drop dead any time, it came as a real shock.

I really struggled through surgery, recovery and my four week admission to hospital over transplant. I hated how I felt physically and mentally and certainly felt devalued at times by various procedures and the occasional nurse. Although of course the majority of the nursing and medical staff were unbelievably encouraging and supportive.

I am so blessed to have been under the care of Professor Peter MacDonald who also looked after my Father all those years ago – he now cares for my daughter too and has been an absolute blessing to my family.

Recovery was long and challenging. Something I hadn't predicted.

The medication side effects still present plenty of challenges for me, however now I am physically able to do more than I ever have in my life.

Something I regularly enjoy now are bush walks with my family. It is amazing to walk along and be able to take in the scent and sounds of the bush without keeling over with tachycardia and shortness of breath.

I am ever so grateful to my wife, my family and God for keeping me strong through this life of transplant which is not an easy road.



Luka-Angel skydiving



Jazz with Luka-Angel

Breathing new life in Australia

From near-death to renewal, my transplant journey gave me purpose—and a place to call home..

By Tracy King | Lung transplant

I have always considered myself one of the lucky ones. I had a very happy childhood, loving parents and siblings, great friends and lots of opportunities. This continued when I became an adult and met my husband, Ian, and had two amazing children, Hallie and Luke.

My health had always been very good and I was able to partake in sports and physical activities. Little did I know what lay ahead.

In 2007, during a routine health exam, my GP gave me a breathing test. It detected that my breathing was not what it should be for a woman of my age and physique.

He referred me to a lung specialist for future examination. I was put through a number of tests by this doctor, but she was unable to definitively diagnose my illness, so referred me on to a lung clinic for review.

Two years later, I was finally diagnosed by a lung disease specialist and told that I had Pulmonary Arterial Hypertension (PAH) and it would be treated by medication.

I should share with you that all of these medical services were provided to me in the United States. I am an American citizen and my husband, Ian, is an Australian citizen and we were living in the United States at the time.

I spent the next twelve years being treated for PAH and while I was unable to do strenuous exercise or activities, I still had a decent quality of life. Unfortunately, things took a down turn in 2023 and I started to have a tougher time breathing.



L–R Teresa Cunningham, Tracy, Toni Phillips, Paula Hogan, Crista Bazoian and Cathy Konstantin. *"As you can see I am a lovely shade of blue prior to my transplant."*

My medications were changed and I was waiting for a new medication that was to be approved in the US in March 2024. My US doctor had been involved in the drug trials for this medication and he thought it would greatly improve my quality of life.

In the meantime, Ian and I decided to plan for the future and we purchased a home on the Mornington Peninsula, south of Melbourne. We hoped to spend part of the year in Australia and part of the year in the US.

Having been cleared by my lung doctor to travel to Australia in December 2023, we came over to set up the house and spend the holidays with our children, their partners and Ian's family. However, things did not go quite as planned.

We arrived on the 13th of December, and upon arriving, I was feeling very tired but assumed it was due to jet lag.

I took the next day or so to rest and adjust my schedule to Australian time. Unfortunately, the tiredness continued and I found that I was unable to participate in various activities.

I began to feel very unwell and finally agreed to go to the hospital to be checked out.

My US lung specialist had always told me that I should go to The Alfred if I needed medical care, because it is world renowned and he knows Trevor Williams, the Director of The Alfred Heart & Lung Transplant Program and Respiratory Medicine.

Thankfully, we live about an hour and a half from the hospital so off we went.

The next 24-48 hours were touch and go. My organs had begun to shut down due to lack of oxygen in my blood.

The staff in Emergency Department at The Alfred worked tirelessly to save me and get me stabilized.

When I came out of sedation I did not realize what had transpired, but I could tell from the look on my family's faces that it was a very tough time for them.



Shortly after becoming stabilized, the respiratory doctors began to talk to me about my options going forward. It was determined that any return to the US would be highly risky.

In addition, it was unlikely that I would live for very long continuing to treat my PAH with medication. The only viable option was a lung transplant.

This is the first time a transplant had been mentioned to me or my family, and it came as quite a shock.

The transplant process was explained to me and I was told that I would have to get approved to be placed on the transplant list. This did not come without some barriers, but fortunately after extensive interviews and conversations, it was determined that I would be placed on the list.

Given the state of my health at this point, I was listed as needing a transplant as soon as possible. The stars aligned on January 12, 2024 and I was told that I would be having a transplant the following morning.

We really didn't have time to prepare for anything, but we didn't care – we were so grateful to get this news.

I had my surgery on January 13, 2024. It was a long procedure and I had some complications afterward which kept me in ICU for an additional two months. I had to relearn to swallow, talk and walk.

That is all behind me now and I am doing incredibly well. I am able to participate in activities that I could not do when I had PAH.

I will be forever indebted to The Alfred and all its doctors, nurses, physios, OT's, Allied Health professionals, pharmacists and others who cared for me, listened to me and supported me.

The medical care I received was exceptional. I cannot believe the level of dedication and professionalism that is exhibited in the Australian healthcare system.

As it turns out, it has been determined that my healthcare needs are to remain in Australia for the foreseeable future, which I am very happy about.

Now that I have a second chance in life, Ian and I have reassessed our priorities and look forward to our future.

In an effort to give back I have become involved with the *Heart to Heart Respite House* and *Heart Lung Transplant Trust of Victoria (HLTTV).*

I hope I can help to support others on their transplant journey. I have met so many lovely people through this community and feel very lucky to be a part of it.



The miracle of breath

Jasmine's story reminds us that hope, healing and faith can turn struggle into breath and life.

By Janine Joseph | Melbourne writer

It was some years back, in the world before COVID that I wrote about my friend, Jasmine and our chance meeting as neighbours a decade earlier. *(Sunday Age, 25/8/17)*

I recalled the shock I'd felt on learning that this vibrant young woman, here from Adelaide to study music and dance, was stricken with Cystic Fibrosis, the debilitating lung disease that makes every breath a struggle.

I also wrote of her beloved mother, Rosemary who'd died too soon of lung cancer.

Rosemary had been the rock by Jasmine's side as she grew from the adored baby, born under the cloud of CF which had almost claimed her life, to the inspirational woman I'd met on my street. The journey between had been a rocky one that saw Jasmine dealing with an absent father, mental and physical abuse.

After her mum's death it would have been understandable if Jasmine had given up, losing the will to fight, but that wouldn't have been who she was.

Following years of depression she tells me "I knew I was meant for more."

Refusing to be defeated, she went on to honour her mother's legacy and embrace her deep spirituality and tenacity for life.

True to the values she'd inherited from her mother, Jasmine decided she wanted to direct her experience and skills towards helping others.

She pursued studies in neuroscience in order to help women across the globe to heal – to gain more from life. Now, as a master practitioner of Neuro Linguistic Programming, Hypnotherapy, and Timeline Therapy, Jasmine is the CEO of a successful life coaching company.

In March, 2022 responding to my query about the new treatment for CF, Jasmine reported, "I haven't received it yet. I'm hoping, soon."

And then, "I just got the good news! I'm heading to the hospital now!! OMG! I've waited my whole life for this moment!" – and subsequently a few weeks later, "I'm breathing incredibly. Life feels like something I have never experienced. I'm still training my body and nervous system to know I'm safe now! It's such a blessing!"

When I told Jasmine that I wanted to write a sequel to her story, about the new, miraculous treatment, she insisted that it was very much too the deep healing work she'd undertaken that had brought her to this point.

In the end it matters not – she can breathe freely and live the life of which she's only dreamed.

We can never know the power of hope, belief and the inner life. In Jasmine's case it has brought this amazing woman the answer to her prayers. I like to think her mother knows she's "safe now."

In recent weeks since the death on April 24 of my very special friend and DonateLife colleague, Len Hain, I've been thinking of Jasmine again.

For many years Len and I did presentations together to raise awareness of organ donation. Len, a double-lung recipient and myself, a live kidney donor formed an ideal 'double act' to deliver our personal stories of the life-changing impact of transplantation.

I have never forgotten Len's poignant words and one line in particular, that he'd never miss, "When you can't breathe, nothing else matters."

Len could breathe again following his successful transplant of some 23 years ago.

Jasmine can finally breathe freely after waiting her "whole life for such a blessing."

My two friends are testimony to the fact that miracles do happen.



Janine Joseph

FACT

One minute is all it takes to register as a donor

DonateLife VICTORIA

FACT

Up to 7 lives can be saved by a single organ donor

DonateLife VICTORIA

FACT

527 people became organ donors in 2024

DonateLife VICTORIA

I dare to dream

You lead me Doc, and I will follow.

By Shaun Cavuoto | Heart Transplant

In 1987, at the age of 16, I was diagnosed with an osteosarcoma bone tumour below my right knee. I didn't really understand what it was or how to deal with it at first.

I was an active boy. I swam, went fishing, canoeing, camping, played tennis and football on Sundays for Seaton Ramblers, but my passion was rugby union for Port Adelaide Rugby Club. I was captain of my team and played state rugby. My dad was a legend in SA rugby. I wanted to be just like him, play for Manly and one day be a Wallaby.

This "cancer" was aggressive. I was fighting for my life, which resulted in my right leg being amputated above the knee, followed by 11 months of chemo. I made it, grew up fast and thankfully there was no return. My family and friends were amazing.

My dad took me down to the local gym. I was competitive and needed to burn all this energy and, I guess, a little anger. I decided I wanted to become a Paralympian and after a few different sports I realised weightlifting (bench press) was for me. I competed for 10 years in the Paralympic squad, world titles, European titles, Australian titles, and my dream – the Sydney 2000 Paralympics – benching a personal best of 187.5kg. Most importantly, my family and friends were there to see me lift at International level.

I retired from powerlifting in 2004. My next adventure/hobby was supporting my sons in their sporting goals and life achievements. In 2013 I had a couple of blackouts and was diagnosed with degenerative heart disease. I had a defibrillator attached to my heart. I began having more issues in 2019/2020.



It was pretty confronting in ICU, but I just had to keep pushing forward

My heart function was at approximately 14–15% – cardiomyopathy, a common side effect of chemotherapy in the 80's. I was in some trouble.

My doctor discussed with me the possibility of having VADs put in at The Alfred Hospital in Melbourne. After several visits to the hospital in 2020 I was medivac'd to Melbourne. On arrival, day 2, a drain was put into my side and 13 litres was drained from my body. Just after my 50th birthday my surgery was completed. I was in the fight for my life again.

Finally waking up after 18 days in an induced coma, I had tubes everywhere and a breathing machine. After 52 days in ICU I made it to the ward. The medical team and physio were incredible, rebuilding my strength, getting me walking on my prosthetic leg, then moving into an apartment in Melbourne with my sister for 10 weeks to continue my rehabilitation. Finally flying my two sons over to Melbourne gave me a tremendous boost.

Returning to Adelaide, it was time to rebuild my body and get on the transplant list. The team at Hampstead Rehabilitation Centre were amazing. I trained really hard – every session was important.

Being listed on the transplant list in January 2022 was exciting but also daunting. My sisters Karen and Tanya have been incredible throughout this whole journey.

It was mentally challenging waiting for that phone call. Many appointments and trips to Melbourne with my sister, weekends in Port Pirie supporting my sons play football – thanks to my mate Sean – this was the best therapy.

I remember talking to my doctors, them stating, "We don't do this to fail." I replied, "You lead me, I will follow."

I was mentally and physically ready, although I didn't need a dose of Covid at this time. Years of training, discipline and a work ethic installed in me from my father, uncles and family held me in good stead. While holidaying with my sons in the Adelaide Hills at 4pm on Thursday afternoon I received the phone call: "We have a match."

Thankfully my friend Sean was ready to go and left immediately from Adelaide. I was shaking and very emotional saying goodbye to my sons and returning to Adelaide to be flown to Melbourne by the Royal Flying Doctors. Initially we were meant to leave at 9 o'clock, but there was a storm so we couldn't leave until 11:30pm. It was the wildest flight I've ever been on.



One of the best outcomes of this journey has been to get back to supporting my boys (Jack and Henry) and watching them play football.

Arriving in Melbourne, being transported to The Alfred Hospital and getting prepped for surgery at 7am, they wheeled me into theatre. I said a couple of words to the good Lord and off to the happy place I went.

I opened my eyes the following Monday morning. Something didn't feel right. The surgery had been called off at the last minute. I felt some tension in my room, doctors and nurses everywhere – my right VAD had stopped working.

My doctor assured me that things were ok and that he was discussing the plan with the American manufacturers. This was the first time they had seen this. This was a devastating period for myself and my family. I will never forget those words: "We're going to decommission the R-VAD."

On Tuesday morning my doctor/professor explained to me that the donor heart had high cholesterol and was rejected. He assured me that the right side of my heart was working well. I was on the top of the national transplant list to be reviewed in 14 days.

On 22/10/2022, day 14, the medical team came in and told me, "At 4 pm we have a match." Here we go again. Very emotional again, being prepared for surgery, I was wheeled into theatre the following morning and had a successful heart transplant.

After 21 days in an induced coma I finally woke up. I was alive with machines everywhere, in the battle of my life. After I woke up I learned that immediately after my surgery I'd had follow-up surgery three times due to bleeding and fluid build-up.

My first physio session was to start squeezing a glove that one of the nurses had blown up for me, to start building strength. Progressing to brushing my own teeth.

This was another tough 48 days in ICU, unable to talk, feeding tube, I could smell the food cart going past driving me crazy. I was getting stronger and hungry. Thankfully I got regular phone calls, messages and visits from my family and friends (Cuz, Lisa - incredible). Melbourne was in the middle of Covid shutdown which didn't help, so I was isolated for a few weeks. Moving back into an apartment with my sister and flying over my boys finally to complete my rehab.

Unfortunately, my kidneys didn't recover from the surgery, so regular dialysis was needed and ongoing. I

Article continues on following page...

had a further three surgeries from complications from earlier surgery not related to the heart.

After three attempts, my sister for the third time flew over to take me home. Finally I'm back in Adelaide. I had a celebration lunch with family and friends – I'd dreamed about this day. What a crazy few months, hardest thing I've ever done. I was told the first 12 months is hard and they were right, being hospitalised twice with pneumonia and another hit of Covid.

I also bumped my leg, turning into a haematoma resulting in two surgeries and a skin graft. I wondered how much my body could take.

Recovery at my sister's, supported by her family and my friends, I continued my rehab at Hampstead and with my private trainer (Tim from Body Fit Physiotherapy), building my strength and eventually getting back up on my prosthetic leg, still heading to Port Pirie whenever possible to support my boys.

Eventually I was well enough and managed to lease a house, and my ultimate goal of my boys returning to Adelaide to live with me and support them – this was always the plan.

Both my sons are now working. Jack recently worked out of Port Lincoln on a prawn trawler and the tuna harvest, and has been playing football for Elliston.

Henry completed some further studies and will be a second-year apprenticeship plumber soon. He also is playing football with his mates up at Birdwood. We are hoping to purchase a house in the next 12 months.

I'm now walking independently, been driving for 8 months and continue to train 4–5 times a week. I continue to need dialysis weekly and have begun the build-up for a possible kidney transplant.

Everybody has a battle in life. This has been a team effort – I couldn't have done this without the support from my sisters, my boys, family and friends. The medical team at the RAH, The Alfred Hospital, Hampstead Rehab Centre, my personal trainer – I consider myself very lucky. My sons are my inspirations.

In life we get to meet some very special people, influential people. I have met many and I'm very grateful.



Getting ready to depart Adelaide on a RFDS Medivac flight to Melbourne after a storm delay.



Karen and Taynya with me in the Ansett Corporate Marquee at Sydney Olympics



The Sydney 2000 Paralympics was a source of enormous pride in my achievement



Recent news around AlfredHealth

In case you missed it...



The history of 1000 Hearts at The Alfred

The Alfred recently became only the second Australian heart transplant centre to complete 1000 successful heart transplants.

The story of 1000 Hearts starts in 1988, when The Alfred was chosen as Victoria's Adult Heart Transplant Centre.

Since then, the service has grown, and now cares for patients from Victoria, Tasmania and South Australia who have had, or are waiting to have, a heart or lung transplant.

As part of The Alfred's Heart and Lung service, patients now have access to a full suite of complex, acute and general cardiac services from world leading clinicians, at their doorstep.

Over the years, The Alfred has driven innovations in heart transplant care:

- **1989**: The Alfred's Heart Lung Transplant Service commences, and becomes the busiest unit in Australia and South East Asia



An Alfred heart -lung machine in 1963



The hypothermic machine perfusion 'heart in a box'



The Total Artificial Heart

- **1990**: An Alfred team implants the first artificial heart pump in south east Asia and a Thoratec Ventricular Assist Device as a bridge to heart transplantation and the first transcontinental heart retrieval from Perth
- **1990**: A patient is flown from Perth to Melbourne for transplantation in a specially-pressurised RAAF Hercules plane. This heralds the unit's first successful retrieval and later, transplantation of a critically ill patient from across the country
- **1991**: An Alfred team visits another hospital to insert Extracorporeal Oxygenator (ECMO) into a patient who is then brought back to The Alfred for transplantation
- **2005**: The Alfred opens its Paediatric Lung Transplant Program
- **2021**: 'Hypothermic ex-vivo perfusion' is trialled, potentially doubling the time a donor heart remains viable for transplantation
- **2024**: The Total Artificial Heart is launched, one of three heart technologies being created under the Artificial Heart Frontiers Program, based at the Monash Alfred Baker Centre for Cardiovascular Research at The Alfred.

BE THE REASON SOMEONE ELSE GETS A SECOND CHANCE AT LIFE

DonateLife



JAYLYN RECEIVED A HEART TRANSPLANT

REGISTER AS AN ORGAN AND TISSUE DONOR TODAY AT DONATELIFE.GOV.AU

SCAN TO REGISTER



Critical Care Appeal raising lifesaving funds for Mobile ECPR

This year's Critical Care Appeal is fundraising to support Mobile ECPR, an advanced form of life support which takes over the function of the heart and lungs for patients in the community after cardiac arrest.

When 43-year-old Melbourne dad Mark Wohlers suffered a cardiac arrest, it was the swift response from his wife and emergency services, and an Australian-first clinical trial that gave him a second chance at life.

"I went into cardiac arrest on a day when the Mobile ECPR trial was running, and my wife happened to ring and put me in touch with emergency services right before I crashed the car out of the front of my house," Mark said.

"The ambulance then pulled up behind and got me out, and the ECPR team shortly followed."



Dr Sacha Richardson with Mark Wohler

Central to the trial is an advanced form of life support called ECMO (Extra-Corporeal Membrane Oxygenation). Commonly only offered in specialist hospitals, ECMO is a machine that can take over the function of the heart and lungs.

Trial co-lead and intensive care specialist Dr Sacha Richardson said his team had been using ECMO for years in the hospital, but technological advancement meant the machines were now small enough to take to the streets.

"CPR and defibrillation are still the mainstay of cardiac arrest response, but a person's chance of survival falls to less than five per cent if you can't restart their heart within 30 minutes," Dr Richardson said.

Under the trial, two experienced ECMO-trained Alfred intensive care specialists travel with paramedics to a patient identified as a potential candidate.

"In Mark's case the intervention was lifesaving. We were able to attend the scene, insert the ECMO to bypass his heart, and get him to The Alfred where his coronary artery was unblocked, and his heart was restarted.

"We are hopeful our current trial – and possible further and larger trials – will show the practice is feasible, and that it can significantly increase the chances of survival after cardiac arrest in the community."

The Critical Care Appeal is an annual fundraiser which helps The Alfred continue to provide the most critical and complex care to Victorians.

For more information or to donate please visit www.alfredappeal.org.au

www.alfredhealth.org.au

A recent cutting from the **Red Gum Courier** – The Nathalia & District Newspaper

Acknowledgment of Support from Nathalia District Welfare Inc.

Each year, the local Op Shop generously donates funds raised to various not-for-profit and charitable organisations within the region. One of the selected recipients this year was The Heart to Heart Respite House Inc., a non-profit organisation based in Barmah.

On Saturday, 4th October 2025, a presentation took place to acknowledge the significant contribution from the Nathalia District Welfare Inc. Op Shop. Trudi Jones, President of The Heart to Heart Respite House Inc., presented an appreciation certificate to Fay Hutchins and Kerry Rice, expressing heartfelt gratitude for their generous support.

The Heart to Heart Respite House Inc. is a non for profit charity dedicated to providing a respite home for pre and post transplant recipients and their families, offering them a much-needed space for recovery and rest.



L-R: Fay Hutchins, Kerry Rice and Trudi Jones.



HLTTV Merch

If you woul like to purchase one of the T-shirts or Polos (in a range of colours), contact Claude on claude.turco@optusnet.com.au for further details and pricing.

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Watch the video on our website to discover more...



Your host
Robert Rockman



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Stronger with every beat

Through three transplants and countless trials, I've learned that gratitude gives every heartbeat its strength.

By Hannah Tucker | Two heart transplants and a kidney transplant

Hello, my name is Hannah Tucker, and I'm incredibly grateful to be here today to share my story – one that spans over 17 years, 3 transplants, and countless moments that reshaped who I am.

When I was 14, I was a regional netball player—fit, energetic, and full of life. It was during a carnival on Kangaroo Island that my parents noticed something wasn't right.

I lacked stamina, and soon after, I began fainting on the court.

After nearly a year of tests and hospital visits, I was diagnosed with Restrictive Cardiomyopathy, a rare heart condition that stiffens the lower chamber muscles and stops the heart from filling properly. 1 in a million children get this and I was told that the only treatment was a heart transplant.

At the time, I didn't really understand the gravity of it all. I was protected—by the staff at the Royal Melbourne Children's Hospital, by my family, and by the way things were gently explained to me.

At 16, I was listed for transplant and waited 11 months. During that time, I had various treatments—medications, electrical cardioversion (where paddles were used to try and shock my heart back into rhythm), and a defibrillator implant. When I wasn't in hospital, I was trying to finish Year 10.

I'll never forget the day I got the call. I was sitting an exam. A teacher walked in, and just by her face, I knew. I said "No" and tried to walk away. Mum was there and the whole school came out to wave me off. I flew to Melbourne in



Hannah (second from right) at her sister's wedding with her partner Lachlan (end right)

Photo courtesy Dan Evans Photography



my uniform. Dad was still in his work boots. I didn't speak again until we were met at the hospital by a clown doctor.

Recovery went well. I stayed in Melbourne for three months doing physio, I had some rejection issues and seizures, but they were managed quickly. Life began to return to normal. I finished high school and earned a Bachelor of Social Work. I travelled, and even had a Make-A-Wish trip to London where I met the cast of Harry Potter—specifically, Ron Weasley.

When I was 23, my heart began failing again. But this time was much harder. I was tired, swollen with fluid, and in constant treatment. There were moments I couldn't walk. I had three massive boosts of steroids (1000mg each) to try and reverse the rejection, but this inflamed my gallbladder, which had to be removed. Eventually, I was flown back to Melbourne, where I was put in ICU and underwent lots of





procedures and new medications. I was placed on ECMO—(Extracorporeal Membrane Oxygenation)—which is a life support system that takes over the function of your heart and lungs. It gives your body time to rest, but it's usually a last resort. When this did not achieve the desired outcome, I was also given a VAD (Ventricular Assist Device) This is a mechanical pump that take over the work of a failing heart. Quickly, it became clear that further support was needed, leading to the implantation of a second VAD.

Far left: This was me at the Royal Melbourne Children's Hospital before my first transplant.

Left: At the Alfred hospital in Melbourne, I mentioned I missed my dog, so the cardiac doctor went home and snuck his dog into my room.

These devices replaced my heart and I no longer had a heartbeat. I underwent six open-heart surgeries in just six days, and there were no guarantees I would wake up from any of them.

I was completely bedbound and lost all muscle mass. Again, I was no longer able to walk or sit up and I had to relearn all these things before I could officially be relisted for a heart transplant.

Article continues on following page...





Left: Doing dialysis at home. Above: Leaving The Alfred ICU after my heart transplant. Above right: With my family. I caught CMV at Christmas time and a few days later I was placed in an induced coma.



Lachlan and Hannah making the most of their time at the Transplant Games in Canberra in 2024



Winning silver for Indoor Rowing at the Transplant Games

This took about three months, then three days after officially being listed, I received the call for a new heart.

Recovery was slow and complicated. I faced rejection, pneumonia, hair loss and severe pain, and was readmitted for pain management. My mum and I lived in Melbourne for nearly a year while I recovered. Eventually, I got back on my feet. I moved home to Adelaide, bought a house, returned to work, and became a godmother to my first ever niece.

Then at 28, I caught CMV, a virus that attacked my lungs. I was placed in an induced coma for four weeks. Doctors eventually woke me—uncertain of how I'd respond. I had survived, but my kidneys, which had been grumbling away for some time, hadn't.

I was told I needed a kidney transplant.

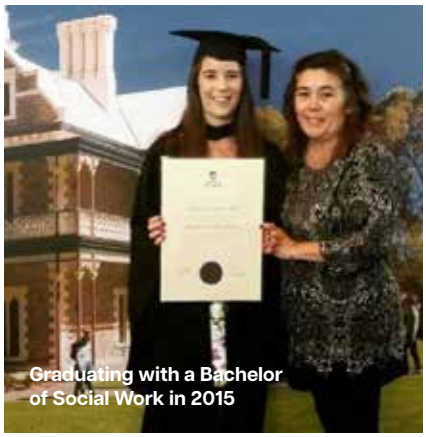
I started peritoneal dialysis at home, which was painful and isolating. My safe space became a hospital. We switched to haemodialysis—four to six hours in a centre, three times a week.

Thankfully after about a year, my mum, who had already given so much of herself to me, was a match, and had been approved to be my living kidney donor. It took a year for her to complete all the required workup.

The surgery was done in Adelaide, which meant we were closer to family and friends.

Since then, I've done things I never imagined. Last year I went to the Australian Transplant Games in Canberra with Mum and my partner. I met incredible people—and even won gold in pétanque and ten-pin bowling, and silver in indoor rowing. I hadn't been good at sport since I was 14, so those medals were very special.

Today, I feel well. I live with necrosis in my bones from long-term medication, but I'm strong. I go to the gym with my sister. I have a partner who understands my journey because he's lived through something similar. We recently moved in together, and I feel very lucky.



Graduating with a Bachelor of Social Work in 2015

This December, I'll celebrate 10 years since my second heart transplant, and 17 years since my first. These aren't just numbers—they're proof of what organ donation can do.

One of the biggest joys since transplant has been becoming a godmother to my niece and watching both her and her brother grow. None of that would have been possible without that first transplant back in 2008.

To my donor families: I've written letters of thanks, but there are no words powerful enough to express my gratitude for their selfless gift. In their deepest grief, they chose to give life—to give me time.

Time to grow, to love, to meet my nieces and nephews, to chase dreams I never thought I'd even get to have.

If someone asked me why they should register as an organ and tissue donor, I'd say this:

Because you won't just change a life. You'll change a family, a future, a community. My life—and my family's life—has been made possible because someone said yes.

Today, I live with gratitude. I love getting older. I love that I get to work. I love my family and friends, I'm passionate about helping others walking a similar path.





Left: Celebrating my kindey transplant with my mum (my donor)

Above: Feeding a big cat at the Monarto Safari Park

Below: Having fun with my niece and nephew Sienna and Marcus.





Kayne Brewster with his wife Alyx and children Lilly and Wyatt. IMAGE BY CHRIS CINCOTTA

A heartfelt wait

"It's a strange feeling... I'm not sick enough to be in hospital, but not well enough to truly live."

There's nothing Kayne Brewster enjoys more than spending precious time with his two young children, Lilly and Wyatt, and his soulmate, Alyx. His family are his biggest focus and greatest love in life.

While he relishes being a stay-at-home dad, Kayne - unlike most young fathers - is on borrowed time. Kayne is waiting for a heart – a gift that will ultimately save his life.

Kayne was born with a rare and life-threatening congenital heart defect known as tricuspid atresia – a condition where the tricuspid valve isn't formed between the two right heart chambers. Without this valve, blood can't flow normally from the upper to lower chambers on the right side of the heart.

At only three days old, Kayne underwent his first open-heart surgery. As a three-year-old, he endured his second open-heart surgery to have a Fontan procedure – a complex operation that creates a new path for blood circulation.

Kayne has lived with reduced heart function ever since. Aside from regular check-ups, medications, and blood tests, Kayne says he still managed to live a relatively normal life - until three years ago when things started to change.

"I started to feel weak, lethargic, and sluggish", says Kayne. "Alyx could see something was wrong when my lips would turn blue and my colour would change."

Kayne's heart was failing. With his heart working harder than ever – his medical team compared his heart to that of an



Kayne as a child after his second open-heart surgery

elderly person - Kayne was officially placed on the waitlist for a heart transplant. That was in January 2024, only a month after the birth of Kayne and Alyx's second child.

"It's a strange feeling, waiting for a heart," Kayne says. "I'm not sick enough to be in hospital, but not well enough to truly live. So, you wait, and you hope, and you try to stay strong. For your kids. For your partner. For yourself," he says.

Meanwhile, they take short trips away in their campervan, creating special memories together as a family while they wait for the call. It's not easy emotionally, physically, or financially, says Kayne, but hope for a brighter future stays with him.

"For us to go forward as a family we need this operation," says Kayne. "It could mean I get to stay and see my children grow up. I'm ready."

It only takes one minute to register as an organ and tissue donor at donatelife.gov.au or through MyGov. Then, tell your family you want to be a donor.

Fast Facts
Organ and Tissue Donation

- There are currently around 1,800 Australians on the waitlist for an organ transplant and 14,000 more on dialysis for kidney failure who need Australia's help.
- One organ donor can save the lives of up to 7 people and change the lives of many more through eye and tissue donation.
- We know that 4 in 5 Australians say they support donation, but only 1 in 3 are registered on the Australian Organ Donor Register.
- Sadly, around 50 people die each year on the organ transplant waitlist.
- In Australia, your family is always asked to agree to donation. They are much more likely to agree if they know you want to be a donor.
- Around 8 in 10 families say yes to donation when you are registered, but this drops to 4 in 10 when they don't know what you want.
- **It only takes one minute to register as an organ and tissue donor at donatelife.gov.au or through MyGov. Then, tell your family you want to be a donor.**

SCAN THE QR CODE BELOW FOR EASY REGISTRATION

DonateLife VICTORIA



The journey continues: life after transplant

Long after surgery ends, our care continues—empowering transplant recipients to live fully and thrive.

By Laura Sadler and Louise McIvor | *Heart and Lung Transplant Program, Royal Adelaide Hospital, Adelaide*

The Heart and Lung Transplant Program at the Royal Adelaide Hospital (RAH) is a unique, collaborative service that supports patients across South Australia and beyond.

As a non-surgical, satellite program, we work closely with interstate surgical transplant centres while delivering the ongoing outpatient care, monitoring, and rehabilitation that's essential to long-term transplant success. Importantly, this model of care allows South Australian transplant recipients to remain at home with their families and loved ones while waiting for transplantation, reducing the burden of relocation during an already challenging time.

Though heart and lung transplant recipients share many aspects of post-operative care—such as immunosuppression, infection prevention, and routine monitoring—each journey also has its own distinct milestones.

From lung function testing and bronchoscopies to heart biopsies and echocardiograms, the path to recovery is shaped by the needs of the organ and the individual.

As nurse consultants in the Heart and Lung Transplant Program at RAH, we have the privilege of walking alongside patients and families as they adjust to life after transplant. In this article, we share an overview of post-transplant care, highlighting both the shared experiences and the unique considerations for heart and lung recipients.

Whether you are newly transplanted or years into your journey, our goal is to help you feel informed, empowered, and supported every step of the way.

Shared Foundations of Transplant Aftercare

For heart and lung transplant recipients, the foundation of recovery begins with consistency in medication, close monitoring, and a team approach to health and wellbeing. Immunosuppressants, including tacrolimus and mycophenolate, help prevent rejection, while low-dose steroids are often continued long-term for lung transplant recipients to



Above and facing page: Louise catching up with patients in the Heart and Lung Transplant Program rehab gym at the Royal Adelaide Hospital

donatelife

It only takes one minute to register as an organ and tissue donor at MyGov or via donatelife.gov.au. Then, tell your family you want to be a donor. Think about it today.

Article continues on following page...



Left: **Laura Sadler** – SA Lung Transplant Nurse Consultant
Right: **Louise McIvor** – Heart Lung Disease Nurse Consultant
Laura and Louise work in Central Adelaide Local Health Network's Heart and Lung Program

manage inflammation and reduce airway rejection risk. Routine blood tests monitor kidney and liver health, drug levels, and infection markers, helping the team tailor care to each patient.

Infection prevention is critical, particularly in the lungs where the risk of inhaled pathogens is higher. Vaccination (against COVID-19, influenza, and shingles), hand hygiene, and staying away from sick contacts are all essential steps. Partnering with patients and families through education and shared decision-making helps reinforce these protective strategies.

Allied health plays a pivotal role in supporting holistic recovery. Dietitians guide patients through post-operative nutrition needs.

Physiotherapists assist with breathing techniques and activity plans, while social workers and psychologists provide emotional and practical support.

Every patient's journey is unique, and involving carers and families ensures that goals and challenges are shared, understood, and supported.

Organ-Specific Monitoring and Milestones

Monitoring lung transplant health requires a multi-layered approach. Bronchoscopies are performed regularly in the first year to detect signs of rejection or infection through sampling the airway (bronchoalveolar lavage & Transbronchial Biopsies).

Lung function testing—particularly FEV1 and FVC—becomes a crucial part of daily and clinic-based monitoring, often giving early clues if something isn't quite right.

Similarly in heart transplant, cardiac biopsies are performed regularly within the first year to detect signs of rejection and inflammation through sampling of the heart tissue (Endomyocardial biopsy).

Other cardiac investigations¬—particularly Echocardiogram and Exercise Stress Testing or CT Coronary Angiogram—are fundamental and routine aspects of long-term monitoring, performed to detect any early acute changes or abnormalities such as blockages or chronic rejection.

Imaging such as chest X-rays or high-resolution CT scans also helps detect infections, fluid build-up, or chronic changes.

These tools help the team identify issues early, but they're most effective when patients and families are actively engaged—monitoring symptoms, tracking spirometry readings or vital



Laura (left) and Louise analysing a patient's scan

signs at home, and reporting any changes promptly.

Medication Management – Similar Regimens, Different Paths

While lung and heart transplant recipients often take similar core medications, long-term plans diverge.

Lung recipients typically remain on daily low-dose steroids to manage ongoing airway inflammation and mitigate rejection risk. Whereas heart recipients are reviewed on an individual case-by-case basis, with factors such as rejection episodes or donor-specific antibodies determining whether recipients remain on daily low-dose steroids or not.

This long-term steroid use can bring side effects such as mood changes, osteoporosis, or weight gain.

The transplant team supports patients through these challenges by adjusting medications, recommending bone health strategies, and offering ongoing education.

Being proactive with medication routines, knowing your levels, and involving carers in medication management—especially during times of illness or travel—helps reduce the risk of complications and empowers patients to take ownership of their health.

Rehab and Recovery

Pulmonary and cardiac rehabilitation is a vital part of transplant recovery, beginning as early as the pre-transplant phase and continuing well into the months following surgery.

After transplant, rehab focuses on rebuilding physical strength, improving respiratory and cardiac function, and gradually increasing endurance.

This structured approach not only enhances physical capacity but also contributes significantly to overall wellbeing and long-term outcomes.

Rehabilitation is more than just exercise—it's about regaining confidence in movement, managing fatigue, and re-establishing a sense of independence.

By working closely with physiotherapists and setting achievable goals, patients can improve their quality of life and return to meaningful daily activities. Families and carers also play an important role in supporting motivation and consistency throughout the recovery journey.



Laura overseeing a respiratory patient performing a lung function test

The Role of Surveillance

Surveillance is our safety net. For lung recipients, a sudden drop in FEV1 may indicate infection or rejection and warrants prompt review. While changes in sudden or unexpected weight gain, swollen ankles, palpitations, dizziness or fatigue will require escalation as it may indicate rejection for heart recipients. Blood tests track tacrolimus levels, white cell counts, and kidney function to guide medication adjustments and monitor for side effects.

Daily spirometry, measuring vital signs, symptom diaries, and early reporting of changes are all examples of how patients and families contribute to safe, proactive care. The partnership between the transplant team and the patient's support network is central to picking up subtle warning signs and responding early.

Immunity and Infections

Infection is a considerable risk in both heart and lung transplant aftercare. Specifically in lung transplant, the lungs are exposed to the external environment with every breath, creating a high risk for infection. The transplant teams take special care to balance and mitigate the risk of infection whilst simultaneously preventing rejection. Prophylactic antibiotics, antivirals and antifungals are part of routine care. Education on safe food handling, avoiding crowded indoor spaces, and staying up to date with vaccinations are also key strategies.

Families and caregivers are encouraged to be vaccinated as well—this creates a "circle of protection" around the patient. Travel, returning to work, and social events are all possible, but need planning and shared discussions with the transplant team. Together, we balance independence with safety, always prioritising long-term health.

1,000 hearts for Laura

In a quiet act of remembrance and kindness, Kerri Daw has found a way to honour her daughter Laura Benham's legacy – by handcrafting and distributing tiny fabric hearts.



Laura (pictured) was a much-loved teacher, mother and member of her local community. Laura was diagnosed with an aggressive lung condition and although she received a lung transplant, she died after only a short time. In a final act of generosity her family honoured her wishes and Laura herself became an organ donor, saving the lives of others.

Inspired by the global 'Tiny Hearts' kindness movement, Kerri began making small hearts to give away. "It's my way of keeping Laura close and giving something of her to others," she says.

The hearts have been shared with community groups, including the HLTTV, as well as with the Alfred Lung Transplant unit where Laura received her care.

Each year, Kerri also makes embroidered hearts for the new prep students and mothers at Laura's former school.

The school's principal, Hayley, looks forward to receiving them annually. The initiative has even reached as far as Belfast, offering comfort to young transplant recipients and their families.

Laura's school community continues to honour her memory with an annual "Orange Day," raising funds for the Lungitude Foundation to support lung transplant research and care.

Known for her positivity and compassion, Laura left a lasting impression on those around her.

She was the sort of teacher who wrote personal letters to each student and delivered care packages to those in need. Her family describes her as someone who "saw the best in everyone" and was deeply devoted to the people she loved.

Through every stitch, Kerri's hearts carry forward Laura's spirit—one of generosity, love, and community.




1000 hearts
made by, Kerri Daw

Are you a Carer in South Australia?

A Carer is someone who helps a family member or friend with:

- emotional support
- grocery shopping
- preparing meals
- medical appointments
- administering medicine
- personal care
- paying bills
- help to communicate

Is this you?

Free support is just a phone call away. Contact Carers SA via Carer Gateway on 1800 422 737 or visit carerssa.com.au

Carer Gateway
An Australian Government Initiative

Carers SA Australia

Are you a Carer and do you know what support is available to you?

If you provide personal care, support and/or assistance to family or friends who live with:

- Disability
- Mental illness
- Dementia
- Chronic health conditions
- Terminal illness
- Alcohol/drug related issues; or
- Frailty due to age

Then you are a Carer and can access supports and services that Carers SA offer.

People become Carers in different ways: sometimes they start helping someone bit by bit; sometimes it happens suddenly, because of an accident or illness. Carers can be any age and any status - parents, grandparents, partners, siblings, children, friends and neighbours may all take on a caring role at some point in life.

Carers SA is a statewide organisation dedicated to supporting Carers in all regions of South Australia, providing services and support for Carers across the state.



Free support is just a phone call away.

Contact Carers SA via Carer Gateway on 1800 422 737 or visit carerssa.com.au

Carers SA - Here for you









If you provide assistance to a family member or friend who is frail due to age, has a disability, a drug or alcohol related problem, is experiencing mental illness or has a chronic health condition, Carers SA is here to support you.

Carers SA is the peak body in South Australia for Carers. We advocate on behalf of all Carers to influence policies and improve support services. Carers SA is the lead Carer Gateway provider in South Australia and provides a range of supports for Carers including Young Carers.

Carer Gateway support services:

- **Carer support** - assisting Carers to determine what they need.
- **Tailored support packages** - enables Carers to access equipment, planned respite and other services to support their caring role.
- **Counselling** - support Carers to talk through their concerns and worries.
- **Peer support** - where Carers can meet with people in similar caring situations.
- **Emergency respite care** - to make sure the person cared for will be looked after if an urgent or unplanned event occurs and stops the Carer from being there.
- **Coaching** - identify personal goals and create a plan to reach these goals.
- **Advice** - provides information on services and support available.

Carers SA also offers:

- **Carer breaks** - providing Carers with a short break from their caring role, funded by the State Government, Department of Human Services.

For further information please contact Carers SA via Carer Gateway on 1800 422 737 or visit www.carerssa.com.au

Carer Gateway
An Australian Government Initiative

Carers SA Australia



Connecting with others and sharing your transplant journey can be a great way to boost your mental health and build new friendships.

A group of South Australian heart and lung recipients and family members caught up recently in Norwood, just out of the Adelaide CBD. This is part of an organic group that meet together periodically to gain support and friendship. Like in other parts of SA, Victoria and Tasmania, many people form stong connections with other who have gone through transplant and become close friends.

Left to right: Peter Dermis (husband of Mary), Mwape Makwaza, Mary Dermis, Hannah Tucker, Lachlan, Dan Farmer, Andrew Hunt, Veronica Pearce (sister of Lyall Pearce, not present), Sushil Kaur, Sue Paparella (mother of Lachlan), Sean Cavuoto, Vanessa Gale, Phil McDonald.



Join the Lungitude Online Peer Support Network and connect with other lung transplant patients and primary supporters.

We recognise that there is a need for further support for patients beyond just the physical, and that every lung transplant patient has a primary supporter who also needs support. We have established a Lungitude Online Peer Support Network, in collaboration with Lung Foundation Australia, to enable the sharing of ideas and tips for managing the practical and emotional challenges of the lung transplant journey.

You will be able to chat with other patients or primary supporters at anytime, explore helpful topics, listen to monthly webinars and hear from guest experts. The community will drive the content.

Please note that this Network is for mutual peer support. It is not a space to provide counselling or medical advice.

Application form at: https://www.lungitude.com.au/peer-support/

News snippets

It's like 2019 – and I still haven't purchased a rocking chair!

Andrew Hunt is a HLTTV member who has provided updates to our readers on his heart transplant journey since 2008.

"This is just a short update to my previous four stories since my 2008 heart transplant.

My previous two stories can be found in the Circulator First Quarter 2016, issue 83, at page 5 and the Spring Edition 2019, issue 97, at page 6.

I cannot locate my first two stories written closer to my heart transplant that were previously on the website.

I turned 69 in February 2025, something that seemed impossible particularly prior to my heart transplant in January 2008, when I was severely unwell.

I am enjoying good health, right now. I am still attending gym and doing my usual treadmill and a few weights, although have slowed-up considerably since those crazy days when I was capable of regularly power walking 8 kms in just under an hour – these days, this sort of speed is beyond me!

I retired in January 2022, after working part-time in a Not for Profit, assisting mature age clients access training subsidies/career and employment support.

We tend to have a quiet life and haven't done any recent travel. In 2021, we visited some friends in the South East of South Australia who have had heart, kidney and liver transplants – so we have plenty of things in common when we get-together!

While we have a quiet life, and I still don't own a Rocking Chair!"

All the best to everyone,
Andrew and Dana



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, dumbells).

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', information from Donate Life regarding organ donation along with a booklet on other financial and social support services.

Peer Support

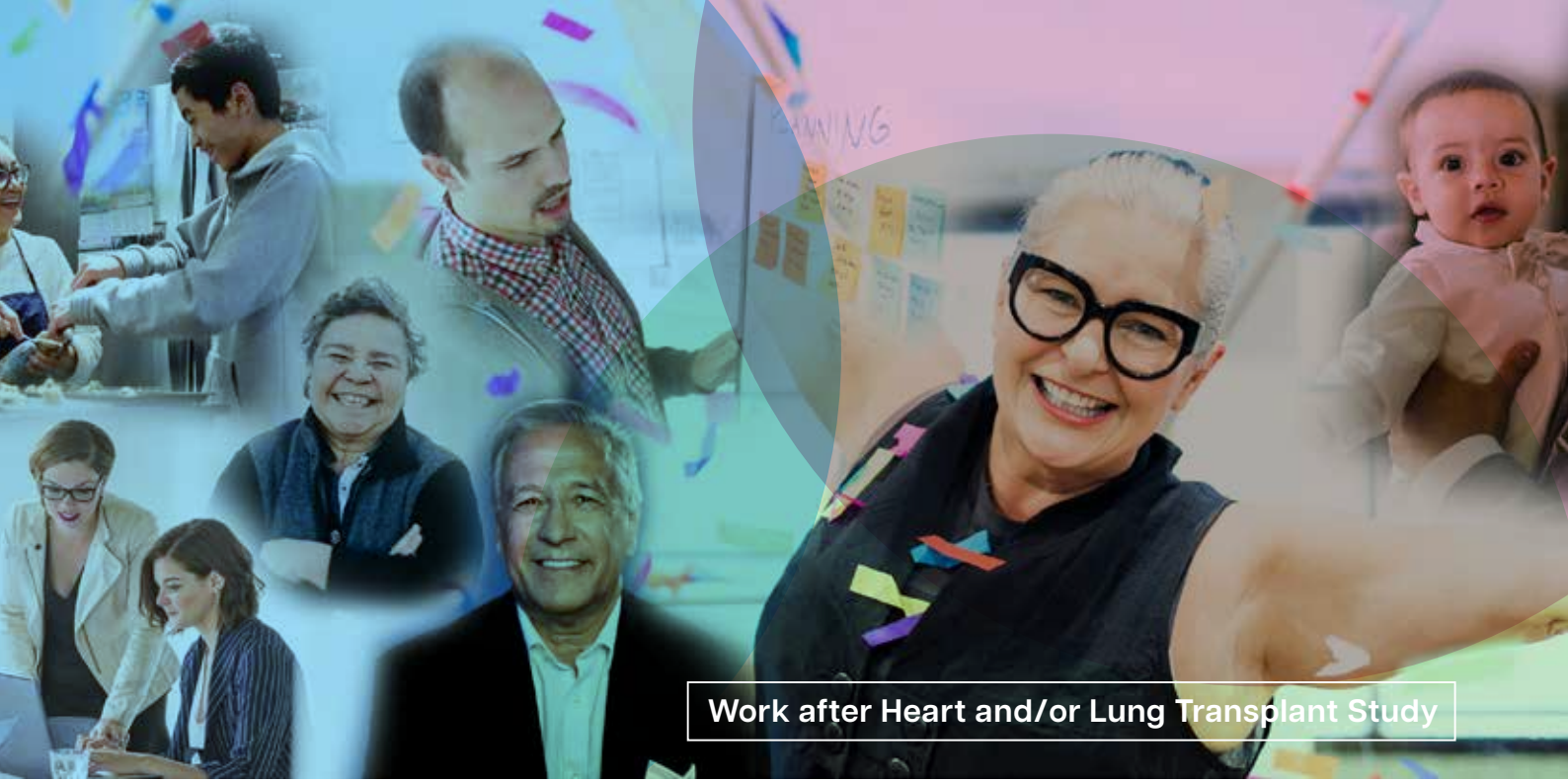
Connecting with other transplant patients either leading up to or post-surgery is an important way to understand and navigate the challenges you will face on your journey. HLTTV can provide information, contact points and assistance for patients wishing to connect.

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 to The Alfred Hospital and a Gala Dinner which acts as a major fundraiser for the Trust. We can also assist members with regional events.

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

Visit us at www.hlttv.org.au



Work after Heart and/or Lung Transplant Study update

The Work After Heart and/or Lung Transplant (WAHLT) Study is a research project aimed at understanding how transplant recipients engage with work—both paid and unpaid—after transplant.

Led by the heart and/or lung transplant community, in collaboration with the Heart and Lung Transplant Trust, Transplant Australia and researchers at Monash University, the WAHLT study explores what heart and lung transplant (LHT) recipients think about returning to work, their lived experiences, and their emotional and physical challenges.

The study also identifies key barriers and enablers that influence their ability to re-enter the workforce or contribute through unpaid roles.

Importantly, WAHLT seeks to uncover what kinds of support and resources would be most valuable to recipients, and when during their recovery these supports might be most useful.

Participants in the study have provided a wide range of insights. Some have spoken about how work helps them reconnect with life and regain a sense of purpose.

Others have highlighted the importance of having a supportive and understanding employer, especially when navigating the physical and emotional challenges that can come with work after transplant.

For some, re-engaging in work is a way of giving back, of contributing to society and feeling 'normal' once again. Recipients spoke about the benefit of receiving information about work at various stages, before and after transplant.

Some participants wanted to receive this information from health professionals, either in clinic, or as part of the rehabilitation process.

Other participants found it most helpful to receive advice and mentorship from fellow heart and/or lung transplant recipients.

In addition to conducting interviews with transplant recipients, we've been analysing the academic literature to assess what has already been published in this area.

This dual approach—combining lived experience with existing research—will help us identify what kinds of resources and support are most valuable to transplant recipients, and when in their recovery these should be offered.

We anticipate finishing the first stage of the WAHLT study at the end of 2025.

WAHLT has received initial funding from the Foote Foundation through the Lord Mayor's Charitable Trust.

For more information please contact Tessa Keegel at: tessa.keegel@monash.edu for more information

This project is being funded by the Lord Mayor's Charitable Foundation,
Monash University Human Research Ethics Project ID: 43707

HLTTV
Heart and Lung Transplant Trust (Victoria) Inc
Bringing The Alfred transplant family together

MONASH University

transplant australia
make the most of life.

2024 Donation & Transplantation Activity Report

In 2024 we continued to move towards pre-COVID-19 levels of activity, with a 3% increase in the number of people who became organ donors compared with 2023.

Thanks to 527 deceased organ donors and their families, and 253 living donors, there were 1,581 Australians who received a life-changing organ transplant last year.

Additionally, there was a 3% increase in tissue donors compared with 2023. The lives of 8,192 people were enhanced when they received tissue from both living and deceased donors. There were 2,630 people who had their sight restored through a corneal transplant in 2024, a 6% increase compared with 2023.

I extend my heartfelt gratitude to all donors, and their families, who said yes to donation and gave others a second chance at life.

Despite organ donation rates increasing since the onset of COVID-19 in 2020, Australia's consent rate remains low. In 2024, 53% of families said yes to organ donation in the hospital, a drop from 55% in 2023, and well below the pre-pandemic consent rate of 60%.

Our national program in hospitals saw the highest number of potential donors in 2024. Only 2% of people die in hospital in a way that organ donation can be considered, so increasing the consent rate within this small group of potential donors – around 1,600 in 2024 – is critical for future growth in donation and transplantation.

We know 4 in 5 Australians say they support donation, but only 36% of the population aged over 16 are registered. Registering as a donor and talking to your family about donation has a direct impact on the consent rate. Around 8 in 10 families agree to donation when their family member is registered. This drops to 4 in 10 families when they don't know if their family member wanted to be a donor.

For around 1,800 people on the organ transplant waitlist, and an additional 14,000 people on dialysis, receiving a transplant can be a matter of life or death. Additionally, with the growing prevalence of kidney disease in our community, we need to increase consent to further increase organ donation and transplantation rates.

Lucinda Barry AM
Chief Executive Officer
25 February 2025

DonateLife

Take a moment to support the supporters

The heart and lung transplant community continues to grow each year and provides significant support to patients, carers, families and clinicians to improve and save the lives of those experiencing a wide range of respiratory and cardiac conditions.

Each of the charitable organisations that exist to support the transplant community, including Lungitude, the Heart & Lung Transplant Trust of Victoria, the Australian Heart and Lung Transplant Association, and Lung Foundation Australia need ongoing financial support from the government, corporate and public sectors in order to further develop their particular focus areas.

Lungitude are proud to support world-class lung transplant research and continues to be a major benefactor of The Alfred's lung transplantation program – the premier service in Australia and 5th largest program internationally

www.lungitude.com.au

The **Heart & Lung Transplant Trust of Victoria** play a vital role in assisting heart and lung transplant recipients and carers with financial assistance for accommodation post transplant as well as funding resources for the Alfred Hospital's transplant program.

www.hlttv.org.au

The **Australian Heart and Lung Transplant Association** (AHLTA) supports recipients, families, and carers through every stage of the transplant journey.

We're a member-led organisation built on lived experience. We're here to connect, advocate, and provide practical help when it matters most.

www.ahlta.com.au

Since 1990, **Lung Foundation Australia** has paved the way as Australia's leading organisation for lung health. We remain dedicated to creating better lung health for all Australians, improving the lives of those living with or impacted by lung disease and lung cancer.

www.lungfoundation.com.au

Mayhem in Morocco: Medication gone missing

Some things are not about money David.

By Tessa Keegal | *HLTTV President*

I recently had the opportunity to go to Morocco for work. My husband David was able to tag along, and we took a few days to visit rural Morocco.

This was every bit as exotic and exciting as it sounds, although some parts of it were also a little scary. We had a driver and tour guide, called Ahmed, who took us around in an eight-seater van with a few other friends.

One morning we decided to visit a fossil museum. Now being the responsible transplant recipient that I am, I thought it was probably safer for me to bring my medication into the museum with me rather than leave it in the van. The van, when parked in the sun, turned into a solar powered oven and I wasn't keen on slow roasting my meds.





Our wonderful tour guid, Ahmed

The fossil museum was fascinating. As you can see from the photo, there were huge fossils of long dead marine creatures. David said to me that he would look after my tablets in the museum. This is a photo (left) of David standing next to a fossil holding my green bag full of meds.

We were ready to get back into the van and I asked David:

"Where are my meds?"

Cue drama, panic, confusion. Somehow a well-meaning museum worker had helpfully put my meds on another tour bus.



Poor David was beside himself, but Ahmed came to the rescue. He whipped out his mobile phone and sent someone out on a motorbike to track down my missing medication. It was a literal desert drug chase.

We soon found out that the medication had been located and a drug hand-off was arranged in the Sahara (yes THE Sahara desert). We wanted to pay everyone involved in our pharmaceutical rescue mission, but after consultation with the others Ahmed said to David: *"Some things are not about money David"*.

As you can see from the photo, David celebrated the moment by riding off into the sunset on a camel.



News snippets

Dental Health post transplant

While transplant medications can weaken bones and affect your teeth, you can take control to enhance your strength and protect your mouth.

Maintaining healthy teeth and gums is an important part of your care after transplant. Not only will you be prone to infections due to immunosuppressants; some of your medications may have side effects that cause gum and dental problems. You need to beware of tooth decay, mouth ulcers, dry mouth, gum disease and mouth infections.

Examine your mouth regularly. Contact your doctor or dentist if you notice chipped or cracked teeth, any swellings in your mouth, ulcers, tooth pain, bleeding; white patches in your mouth, tongue or lining of your mouth.

You can stay on top of this if you visit a dentist every 6 months or more frequently if you develop any infections or problems. Maintaining mouth hygiene is simple: brush after meals and floss regularly to remove particles and plaque.

If you're having any dental work done that may injure your gums, contact your transplant doctor in advance, as you may need to commence antibiotics before the procedure.

transplant australia
make the most of life.

Enhancing engagement with the Patient Portal System among people following heart and/or lung transplant

Assisting patients to manage their own health

By Vicky Yuan
BN (Hons), BEnSc
Registered nurse at Alfred Health, PhD candidate at the School of Nursing and Midwifery, Deakin University

For people living with heart or lung disease, a transplant can be life changing. It brings new hope– improved breathing, renewed energy, and often, a second chance at life. But receiving a transplant is just the beginning of a lifelong journey.

Life after a heart and/or lung transplant is complex. Patients need to adjust their routine, including daily medications, regular check-ups, increased physical activity, and lifestyle changes. This can feel overwhelming. Patient portals can assist patients to manage their health.

Patient Portal

The patient portal system is a secure online website managed by Alfred Health, providing patients with 24-hour access to their personal health information. It allows you to look at your scheduled appointments, inpatient discharge summaries, and Alfred pathology results.

Patient portals help individuals have an active role in their care, improves communication with healthcare professionals, e.g., increases health knowledge, and supports better health outcomes.

About this project

The PhD research project is about understanding how patient portals can support patients following a heart and/or lung transplant. The study aims to explore the experiences of patients and carers about the Alfred portal – *What is working? What is not working? What needs to change?*



This project has three parts:

Part 1: Survey

In Part 1, adult patients who've had a heart and/or lung transplant are invited to complete an online survey. The survey will take about 10 minutes. **Whether you have an Alfred portal account or not, your feedback will help us to understand some of your experiences.**

If you're 18 or older and currently receiving care at the Alfred Heart and/or Lung Transplant Clinic, you are eligible to take part. Carers are also welcome to complete the survey on behalf of their loved ones.

Vicky Yuan, a nurse researcher, attended the Alfred Lung Transplant outpatient clinics between June and October to assist you with the questionnaire and answer questions.

Part 2: Interviews

Patients who have had a heart and/or lung transplant and their carers will be interviewed. The interview will take about 30 minutes, can be held either face-to-face or online, whatever works best for you. You will chat with Vicky Yuan about how the portal has played a role in your care and what challenges you have faced.

Part 3: Co-design workshops

Co-design workshops will be held in person in a conference room at Alfred Hospital. It will run for two hours, and it will involve around 12 people, including patients, carers, and healthcare professionals.

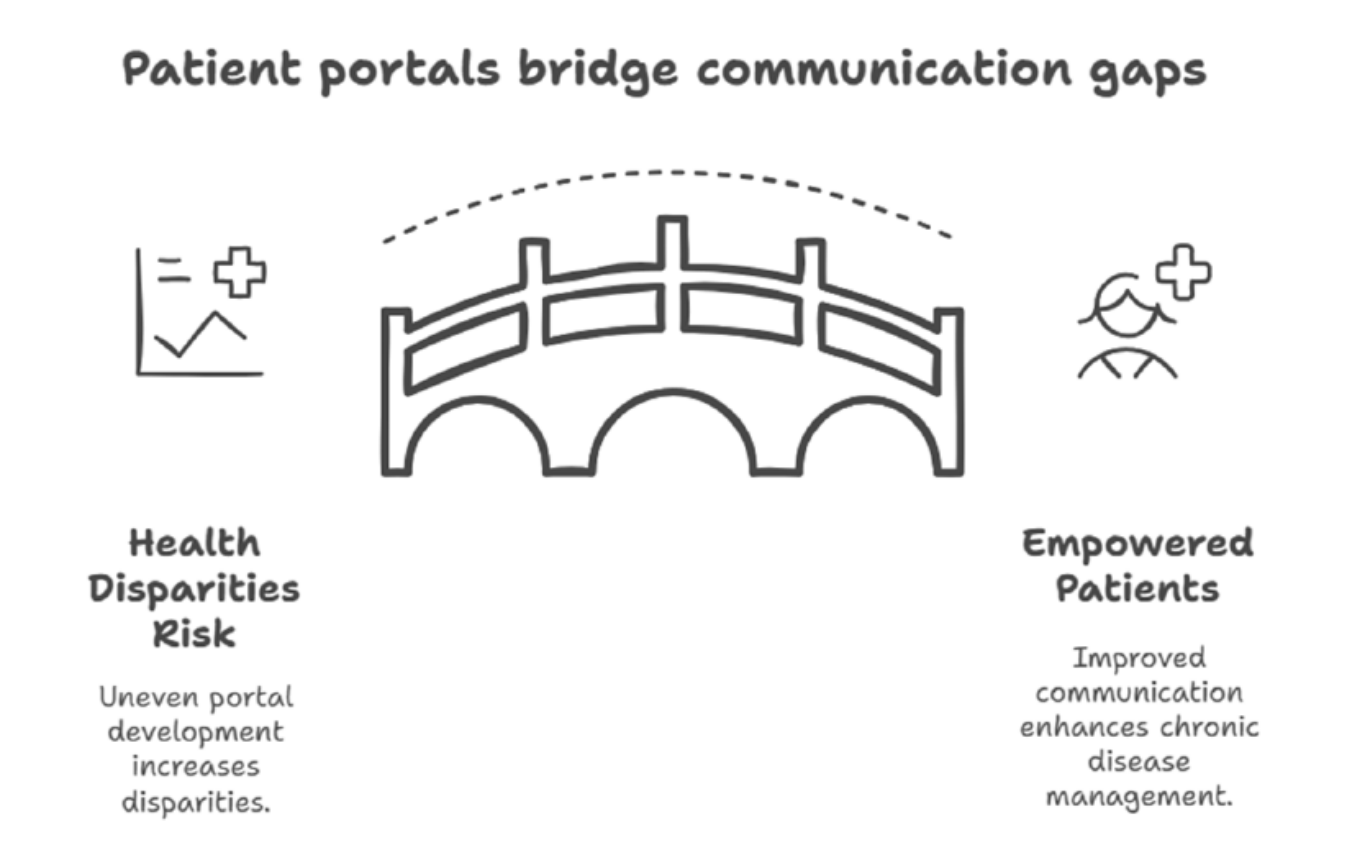
The purpose of the workshop is to involve consumers (patients and their carer) in the portal design. By working together, participants will help develop meaningful recommendations to improve the portal's usability and bridge the gap between digital development and everyday use.

How can you get involved?

If you've received a heart and/or lung transplant and receive care at Alfred Health, your experience matters. We'd love to hear from you!

Participation is entirely voluntary, and choosing not to take part will not affect your treatment or relationship with Alfred Hospital. Patients and carers receive a gift voucher for participation

- In an interview *($40 gift voucher)*, and/or
- Co-design workshop *($80 gift voucher)*.



Graphic generated by: Napin.ai



Vicky has worked at Alfred Health for 10 years. She is passionate about improving patient care and promoting patient safety. In recent years, Vicky has been awarded:

- The Alfred Emerging Researcher Award for Best Nursing Research Abstract 2022
- The Alfred Senior Medical Saff Nursing Research Award for Best Nursing Abstract 2022
- The Alfred Emerging Researcher Award for Best Nursing Research Abstract 2023
- The Carr Family Scholarship for Alfred Nursing Research Honors Degree
- Scholarship for High Degree of Research Deakin University

PhD student: Vicky Yuan[1,2]
Supervisors: Distinguished Professor: Tracey T Bucknall[1,2]
Associate Professor: Debra Kerr[2]
Professor: Elizabeth Manias[3]

1. **Alfred Health**, Commercial Road, Melbourne, 3000
2. **School of Nursing & Midwifery, Deakin University**, Burwood, 3125
3. **School of Nursing & Midwifery, Monash University**, Clayton, 3800





What is the SCAP?

The Second Chance Accommodation Program provided by the HLTTV

Becoming a MEMBER of the HLTTV will assist us to continue to provide funding for this important progam.

See page 75 for the form.

In May 2012, the Heart & Lung Transplant Trust of Victoria (HLTTV) took a bold step and created the Second Chance Accommodation Program (SCAP) by partnering with the Park Regis Griffin Suites on St Kilda Road to secure and guarantee funding for two one-bedroom apartments for a period of 12 months.

These apartments were dedicated for those who need it most – the country and interstate transplant patients.

In an attempt to meet demand, we increased our capacity under this scheme to three apartments in October 2013.

With the great success of our fundraising efforts in 2014 we were able to meet current demand and increase the number of apartments to six.

In 2023 we forged a new accommodation partnership with local providers, Rockmans Apartments, in an arrangement that allows HLTTV to continue to support the program after some very challenging pandemic years here in Victoria.

"The financial assistance from the HLTTV after my husband's transplant was so helpful for our stay. The apartment at Rockmans was beautifully clean."

The apartments provide post-transplant patients with quality accommodation within walking distance of The Alfred. This becomes a place to call home for three months while they go through, possibly, the most traumatic experience of their lives.

There is some financial assistance for those living more than 100km from Melbourne – each State Government pays an allocation per night to cover costs – but sadly doesn't meet the entire cost.

The HLTTV, through the SCAP, is able to contribute towards the shortfall, reducing the overall burden on families.

Over the last decade, HLTTV's average yearly investments have been considerable, typically providing around $2,400 per recipient and carer for the average three-month stay.

The program is administered on a day-to-day basis by **The Alfred Patient & Family Services Department** (social workers).

Any inquiries about availability should be directed through Jane Harris, Social Worker for the Lung Transplant Clinic (03) 9076 2000.

HLTTV SCAP Sponsorship Scheme

Supporting Transplant Recovery

The main fundraising work of the HLTTV is aimed at providing vital financial aid to heart and lung transplant patients and their families, including to support recipients for covering the accommodation costs of staying close to The Alfred Hospital during the compulsory 8-week post-hospital rehabilitation program.

This support is provided through the Second Chance Accommodation Program (SCAP) provided by HLTTV.

Due to limited resources, HLTTV hasn't been able to assist as many transplant patients as we'd like.

To seek to increase the resources available to support SCAP, the HLTTV committee is now developing a sponsorship package to engage corporate partners and philanthropic organisations, trusts and individuals, with the aim of expanding this support.

We hope to have a sponsorship package available in the next few months.

If you know of a company or individual who may be interested in sponsoring this life-changing initiative, please contact James Ure (secretary@hlttv.org.au or uremoilanen@bigpond.com with their details.

Together, we can ensure every patient has access to safe, secure and reasonably-priced accommodation during their recovery.

News snippets

Recognition of Carers

Our wonderful HLTTV President Tessa Keegal's main carer is her husband David Ring. David's strength and gentle humour have carried both of them through Tessa's illness and transplant.

David tells the story of how before her transplant he would memorise every street name just in case he needed to call an ambulance.

David's whole life has changed because of Tessa's illness and she can't thank him enough... although one day he lost her medication when they were travelling in the Sahara, but that's a whole other story (see page 50).



David Ring and Tessa Keegel, the day she left hospital after her transplant, January 2021



Our 2025 Xmas BBQ celebration



Thanks to all of you for your work with the BBQ yesterday. It was so great to see everyone come together to celebrate another year.

We had a number of transplant families attending the BBQ for the very first time, including one person who had a transplant 11 weeks ago and had just come down from spending the weekend at the H2H House in Barmah. They spoke glowingly about how great the house was!

Special recognition and thanks as always to everything that Martina did for the day, the catering and all the set up was wonderful.

Thanks also to James (and his friend Santa Claus), for organising the truck and getting everything from storage and all his work on the day. Santa did a particularly great job announcing all the winning raffle tickets for both the HLTTV and the H2H House raffles.

Thank you to Wanda for sorting out all of the HLTTV raffle tickets, we easily sold our 500 tickets on the day thanks to Wanda's amazing salesperson skills!

Thank you to Tracy for sorting out the H2H House raffle, it was great to see Trudi's amazing handcrafted work going to new homes.

Thanks to Gaylynn for her beautiful christmas cards, such a great initiative and contribution to the HLTTV.

Thanks as always to Sam Ira for his photography work and to Graeme Klemm for creating the flyer.

Please also pass on our thanks to Ross and David for all their work cooking the BBQ, putting things up, taking them down again and packing them away.

Apologies if I have forgotten anyone, it was a wonderful group effort that





shows how amazing we can be when we all come together as a community.

And finally, thank you to the wonderful recipients and families who stay loyal to the HLTTV and support our Easter and Xmas BBQ events.

Tessa Keegel
HLTTV President



















Bowled over by a fantastic event

The HLTTV Lawn Bowling event held at Oakleigh Bowling Club on Sunday 31 August was a successful and fun-filled afternoon.



With about 150 attendees enjoying a fantastic lunch, testing their bowling skills on the greens, and listening to some wonderful transplant stories, there was something for everyone!

HLTTV recognises Angelo Alateras and the committee and members of the Oakleigh Bowling Club for providing us with a wonderful venue and lots of support in planning the bowling event and assisting on the day.

With this support many HLTTV members, family and friends – some skilled and some not-so-skilled were able to hit the bowling greens for a fun filled afternoon.

Martina McArdle and Tracy King planned and organised the wonderful lunch and afternoon tea all attendees enjoyed, and were assisted on the day by other HLTTV committee members and supporters who manned the barbecue, prepared salads, washed dishes, sold raffle tickets and helped with setting up the event and cleaning up at the conclusion of the day.

Of special note were the fantastic transplant stories related by Angelo Alateras and Tracy King to all attendees during the 'formal' presentations as part of the event during the afternoon.

Both stories were heartfelt and moving, and a great reminder to us all in attendance why we continue to support the HLTTV organisation so that it can continue to support transplant recipients, both pre- and post-transplant, and their carers and families.


















Circulator
Circulator


OAKLEIGH
BOWLING CLUB




ORGAN AND TISSUE DONATION
SAVES LIVES


OPEN

The long way back to myself

Pulmonary arterial hypertension may have changed everything – but it wasn't going to have the final word.

By Cassie Sealey

In 2018 I experienced extremely high blood pressure for a long period of time. I was misdiagnosed, and the GP at the time treated my symptoms but didn't look for the cause.

In September 2019 I changed GPs, and the first blood test revealed that I had heart failure. I was then referred to Modbury for an echocardiogram. When the specialist looked at the echocardiogram, he was concerned. It was suggested that I have a further test done to investigate things more. The specialist believed this was urgent, and rather than waiting for the public health system, it was suggested that I book as soon as possible with a private clinic in the city to have another test done.



After completing the test, I returned to the reception area. A specialist met me at the reception desk and suggested that I report immediately to the Lyell McEwen emergency department. That visit to the Lyell McEwen hospital was when I was finally diagnosed with pulmonary arterial hypertension and right heart failure.

At this time I was employed by Anglicare as an aged care support worker. I loved my job and it wasn't something I was going to give up easily. I remember going to my GP every two weeks and asking her if I could return to work, but every time it was the same answer: no. I pushed it out as long as I could, hoping it would go away and life would go back to normal—that I could go back to work and everything else I was doing before.

After months and months of medical certificates, trying to drag out the inevitable for as long as I could, it came to the point where I had no other choice but to resign from my job with Anglicare. I was put on a disability pension.

This was the point when I realised life as I knew it would never be the same again. Not only did I have to resign from my job and leave such a big part of myself behind, I also had to leave the house I lived in with my son. I moved back in with my parents, as I was unable to look after myself and my son, who was then 12 years old.

For about six months I was treated at the Lyell McEwen hospital. After this time I was transferred to see specialists at the Royal Adelaide Hospital, as my condition became more complex and severe. At this point my weight was 129.6 kgs. I was also diagnosed with sleep apnoea and had many hospital admissions throughout the next two years while trialling an array of different medications.

Pulmonary Arterial Hypertension (PAH)

This condition occurs when arteries carrying blood from the heart to the lungs narrow, raising pressure. The right side of the heart must work harder, causing shortness of breath, fatigue, dizziness, chest discomfort, and leg swelling. Over time, PAH can weaken the heart and lead to serious complications such as right-sided heart failure, irregular rhythms, fainting, blood clots, and low oxygen levels, which may become life-threatening.

In August 2021 an angiogram revealed more damage to my heart. This was the day I met Klaire, my pulmonary hypertension nurse. It's also a day I don't think either one of us will ever forget. I was exhausted. I asked Klaire what would happen if I did stop taking my medications, as I couldn't see any positive outcome. At this point my mortality rate was 75%. As you can imagine, this wasn't easy to take in. I met with my cardiologist as well as my nurse to discuss my options.

Number one was the option to lose weight and reach 85 kgs to be fit for a lung transplant.





With my wonderful nurse Klaire

Number two was the option of looking at palliative care.

I wanted to give up. I was depressed, and there was no mental health support suitable for the challenges I was facing

In October 2021 I was given the opportunity to join exercise physiology at the Hampstead Rehabilitation Centre with patients awaiting heart transplants. It was here that I was met with arms wide open, and I made some great connections. I finally felt like I wasn't in this alone.

When I joined the exercise physiology program at Hampstead, the exercise physiologist asked me what my end goal would be, and I replied that it would simply be to be able to make my own bed.



I then saw a heart failure dietitian who helped me plan the next stage of my weight loss journey. Alongside exercise at Hampstead, I was also to start a strict, intense diet using meal replacement shakes called Optifast.

I started my weight loss journey and soon after, on December 17th 2021, I met Ben. The very next day, on the 18th of December 2021, my diet began and my exercise continued.

At this point I couldn't even walk to the letterbox at the end of the driveway. I started by walking up and down the driveway—what was once a day became twice a day, and I increased from there. After pushing myself to walk the length of the driveway, I thought I'd try my luck and walk around the block. I pushed myself a little bit more every chance I could.

I finally started to see and feel the benefits of all the hard work I was putting in. It was at this point I came to the realisation that I didn't want to die. I had so much to live for—my son, my family, and now Ben.

I was monitored on an intense diet alongside exercise for the next four months. With the ongoing support from my pulmonary hypertension nurse Klaire and the connections I made with other patients awaiting transplant at Hampstead, we decided to begin a journey together. To do this, we all downloaded an app on our mobile phones called Strava.

Article continues on following page...

From Ben, Cassie's partner...

Cassie—My Inspiration

Every day I look at you, Cassie, and I'm reminded of what true strength looks like.

You've faced down Pulmonary Arterial Hypertension and right heart failure—something that tried to take so much from you—with a courage that humbles me. You didn't just survive this battle; you won it, with grace, grit, and unwavering determination.

Watching you push forward through the pain, the uncertainty, and the fatigue, refusing to give up even when the path ahead felt impossible—that's something I will never forget.

You've shown me what resilience means, what hope looks like, and how love can fuel even the hardest fights.

I'm beyond proud of you—not just for overcoming PAH, but for the way you did it: with strength, honesty, and heart.

You've emerged on the other side with your spirit shining brighter than ever. You are, and always will be, my hero.

Here's to your victory, and to every tomorrow we get to share because of it.

With all my love and admiration, your number one fan—Ben.

We.Got.This!



From Cassie's mum...

So very proud of Cassie's determination to turn her life around.

It means we have our daughter now looking forward to the future instead of preparing for the worst.

Super proud and so very happy.

This is an app where you can record distance while you're walking, and between each class we would record the distance we had walked.

We had a map up on the wall that showed where we were and the distance to the Alfred Hospital in Victoria, which is where we all needed to be in order to have our transplants.

It was during this time that I finally felt like I wasn't alone. I continued my dieting and exercise, and altered medications along the way. The weight loss finally started, and mobility became easier. With the use of a CPAP machine and oxygen at night, and titrating my medications (which, mind you, were very painful), I started to see results.

I continued exercise at Hampstead until finally I felt I could do this on my own without being monitored and under the watch of professionals. All of a sudden I felt like I'd wasted so many years of my life. Now I could see that life was worth living.

My health continued to improve and I was finally finding happiness within myself. With the support of my partner, my family, and my nurse, I can't even describe in words how grateful I am and how grateful I will always be.

It was only three and a half years ago that I wanted to give up. I just wanted to go away. I didn't want my son to lose his mum. I didn't want my parents to lose a child. The thought of not being there to watch my son grow into the amazing young man he is today absolutely broke my heart.

It has been one hell of an emotional rollercoaster for me, and also for the people I love and care about. It wasn't fair for me to give up and leave so much broken behind me.

Sometimes I felt like I'd let so many people down. No one else understood what I was feeling. Countless times I felt alone, unheard, and misunderstood. I tried to seek some sort of counselling or support, but there was no one that could relate or begin to understand what I was facing or what I was feeling over the last five years. Countless times I just wanted to give up and get it over with.



With my step dad



My nurse Klaire was so supportive

One thing that really got me through was that I had a direct number I could contact my nurse on any day, and I could always call on her for support. She was someone I could really depend on. Honestly, I don't know how I would have done this without her.

As time went on and I became more mobile, I didn't want to sit still. In October 2022 Klaire gave me the idea of participating in volunteer work.

My heart was broken when I had to give up my job in early 2020. That day I found something I thought I would really enjoy, and only two weeks later I was running a café at a community organisation one day a week.

Life just kept getting better and better by the day. My relationships were getting stronger and my health was getting better. We were planning on a family holiday to Bali, but of course I had the burden of not knowing if I was able to fly. If I could do this, it meant I could have an unforgettable holiday experience I never thought I'd have.

I've made more memories in the last three years of my life than I ever have before. Since then I have taken multiple trips to the beautiful island of Bali.

After beginning my volunteer role I just wanted more. In August 2023 I began studying my Certificate in Mental Health. I had a few minor setbacks along the way, and I have just now, in May 2025, completed my qualification.





With Ben and my son, Hayden





While studying, I had the opportunity to take on another volunteer role working for a women's information service, empowering vulnerable women to gain back control of their lives. I run a support group once a week, educating women on self-care strategies and learning new ways to nurture themselves.

In July 2024, after all my hard work and dedication and weighing in at 77 kgs, I was removed from the lung transplant waiting list as my health and quality of life had improved so much.





From Cassie's dad...

Four years ago or so, Cassandra decided to change her direction in life.

So with her interest in community care she applied to do courses that would give her the necessary qualifications and knowledge that she would need.

Cass has a good heart, has a bubbly personality and people know when she steps into a room.

The fact that Cass has those qualifications now, doors will open for her as she is passionate about what she does to help others, now and in the future.

She has compassion, is selfless, outgoing and willing to put the time in to bring about wellness and respect for others.

As a father, I don't think I can be more proud of her and her long term plans for the future.

Note: Pulmonary arterial hypertension is a rare disease in Australia, though its impact is disproportionately felt in certain communities, particularly Indigenous Australians in remote areas.

Article continues on following page...

So this year I have finally had the opportunity to re-enter the workforce. I have now gained employment working in juvenile mental health and supporting children and their families through the challenges and obstacles they face.

My volunteer role at the women's information service has now grown into a management position. I can't wait to use my lived experience to guide me in helping other people who struggle to see positivity and gratitude in their day-to-day life.

After attending the Royal Adelaide Hospital to share my story as part of the consumer experience stories, it was suggested that I use my experience to advocate for patients at the Royal Adelaide Hospital.

I'm now in the process of reducing some of my medications. I'm feeling healthier and stronger physically and mentally than I ever have before. I feel like I'm on top of the world. As hard as the last five years have been for me, I have accomplished so many things and my personal growth has been absolutely incredible.

I attend my local gym almost every day, and I even take part in boxing classes. As hard as this journey has been for me, I believe that I've come out the other side an absolutely amazing version of myself. It's been a road to self-discovery and self-awareness, and



the power of my mindset has pushed me through.

I even participate in burlesque dancing which I began in May 2023,. I have been doing this not only to make friends but to build my self confidence and find passion and excitement for life. I have made so many great connections, built amazing friendships and my self esteem and confidence is forever growing.

To have such a great love for life and all the people in my life, I overcame a long road of ill health and a life of obesity. I did try to give up, but the world had better things planned for me, so here I am—and I'm not going anywhere.

I found the love of my life and he walked beside me every step of the way. Never once has he doubted me or my will to survive. I believe I was



given a second chance—a chance to do things the way I wanted, with the determination and strength to reach goals that would have otherwise been out of my reach.

If anything, this whole experience and battle has made me into a stronger, better version of myself. I love the person I have grown to be. My passion for life and appreciation for every day is indescribable.

Appreciate all that you can. You never know what tomorrow will bring. Never give up. Nothing is impossible.

PS: I can now make my own bed.



Preparing to tell my story to the Communications team at CALHN



HLTTV

We'd love you to share your Transplant story in *The Circulator*



3 SIMPLE STEPS

Step 1

- Write your story in MS 'Word' or something similar (not Publisher).
- You can be as detailed as you want.
- You can write as much as you want.

Step 2

- Include some photos that help tell your story – either historical or recent, it's up to you.
- Please make sure the photos are as high resolution as possible.

Step 3

- Email your story and photos to *The Circulator* editor Graeme Klemm on the email below.
- Graeme will email you a draft to approve before it gets published.

Please direct any questions about how to go about telling your Transplant or circulatory support story to Graeme Klemm on 0421 327 096

Email to: graeme.klemm@outlook.com



Exactly what the name suggests

A respite house for use by pre and post transplant patients and their carers.

The Heart to Heart Respite House in Barmah truly lives up to its name. It's a peaceful, welcoming haven designed for pre- and post transplant patients and their carers—a place to rest, recharge, and gently recover.

Originally established by the late Bill Vickers, the house has been lovingly managed by the dedicated Heart to Heart House Committee since 2024. It's open to all transplant recipients—before or after surgery—as long as they are accompanied by their carer.

Barmah itself is a charming little Murray River town, about 239 km north of Melbourne and just a short drive from Echuca. It's known as the gateway to the magnificent Barmah State Forest, home to the largest redgum forest in the world. The town may be small, but it has everything you need: a post office, general store, fuel, and the friendly Barmah Hotel, which serves delicious, great-value meals (including seniors' options!).

There's so much to explore in the area. Echuca offers historic paddle steamers, a beautiful old wharf, and plenty of shops, cafés, hotels, and even a cinema. A drive through the Barmah Forest is easy in a two-wheel-drive, and the walking tracks are perfect for spotting emus, kangaroos, and even brumbies. Nathalia, just 25 km away, has a lovely bakery, cafés, a few shops and a visitor information centre. Head the other way toward Yarrawonga and you'll come across towns like Strathmerton—home to the quirky and unforgettable "Cactus Country." For those who feel like a wander over the border, charming NSW towns such as Moama, Tocumwal and Deniliquin are all within reach.

The Heart to Heart Respite House
26 Schier Street,
Barmah
Victoria 3639

For bookings and information:
Ph 0468 193 277

or scan the QR code on opposite page

HEART TO HEART RESPITE HOUSE





The respite house itself is thoughtfully set up with everything you might need. It's fully electric and features two comfortable bedrooms (one Queen, one Twin), each with its own TV. The bathroom includes disabled facilities, and there's a functional laundry with a washing machine. The kitchen is fully equipped for cooking and settling in.

The spacious lounge offers plenty of seating, a TV, stereo, DVDs, CDs, and a selection of books and magazines—perfect for quiet afternoons. The dining table seats six, and the house is kept comfortable year-round with an efficient reverse-cycle heating and cooling system.

Outside, you'll find a carport, washing line, an all-around verandah with disability access, outdoor seating, and an electric BBQ—ideal for enjoying the fresh country air.







Guests are only charged $30 per person per night, with an optional $5 per-person linen hire for the entire stay (or you're welcome to bring your own).

Come and spend some time in this beautiful corner of Victoria—almost New South Wales—and see why so many visitors leave glowing comments in the guest book. It's peaceful, welcoming, and truly restorative... a place you'll be glad you visited.

Trudi Jones
hearttohearthousebarmah@gmail.com

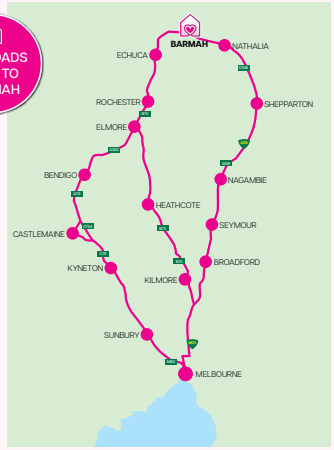




Heart to Heart Respite House
26 Schier Street, Barmah VIC 3639

BOOKINGS:
www.hearttohearthousebarmah.com
Phone: 0468 193 277







Please visit the H2H Facebook page... *Heart to Heart Respite House Inc* for more information.
The link is www.hearttoheart.org.au – past visitors are very welcome to leave comments there.



Post transplant food safety: why it's important

transplant australia
make the most of life.

It is vital to maintain a health lifestyle to protect yourself

Food safety is relevant for everyone but more so for transplant recipients. Recipients are at a higher risk of food poisoning due to immunosuppressants but can reduce the risk of getting foodborne illnesses with a few simple steps.

Ideally, only eat freshly-cooked food and well-washed fruit and vegetables. If there's any doubt about hygienic preparation or storage, don't risk it.

Leftovers can be eaten if they are refrigerated promptly and kept no longer than a day.

Refrain from eating raw shellfish. Shellfish can sometimes carry Vibrio vulnificans, a bacteria harmful to immunocompromised people.

Listeriamonocytogenes (Listeria) is a bacteria found in soil, water and some animals, including poultry and cattle. It can be present in some processed meats and foods made from unpasteurised or raw milk; for example yoghurt or pudding. Listeria loves to grow in the cold temperature of the refrigerator and can be killed by cooking and pasteurisation.

Only keep leftovers in the refrigerator for a day and reheat them thoroughly



Note: Diligently check packaged foods for freshness and bin foods past their 'Use by'/ Expiry dates.

to steaming to kill bacteria. When eating out, order hot meals. Choose menu items that are cooked to order and do not eat food that is served lukewarm.

As a general rule, avoid perishable foods that have been prepared in advance. Ready-to-eat foods from salad bars and sandwich bars may have been prepared and refrigerated some time before they're on display; bacteria may have grown on them, so they're best avoided.

If you plan to eat deli meats, re-cook the meats until steaming. Foods on open display in delicatessen counters like ham, prosciutto and salami are more likely to become contaminated than foods packaged by the manufacturer. Packaged foods like packed salami or smoked salmon are safe.

Remember: Steaming makes it safe.

GOOD FOOD HYGIENE

A few simple steps to reduce the risk of foodborne disease:

- ✓ Thoroughly wash and dry hands before preparing food
- ✓ Keep the refrigerator clean and operate it below 5°C
- ✓ Wash knives, cutting boards and kitchen appliances, and dry thoroughly after handling raw food to prevent contamination of cooked and ready-to-eat foods
- ✓ Thoroughly wash and dry raw fruit and vegetables before eating or juicing
- ✓ Thaw ready-to-eat frozen food in the refrigerator or microwave – don't thaw at room temperature
- ✓ Thoroughly cook all raw meat, chicken and fish
- ✓ Don't leave foods to cool on the bench or stove top. Put them in

the refrigerator after the steam has gone

- ✓ If you are keeping food hot, keep it very hot (60°C +). Keep cold food cold (5°C or colder)
- ✓ Heat food until it's steaming hot
- ✓ Keep stored foods covered
- ✓ Store raw meat separately from cooked and ready-to-eat food in the refrigerator. Store it below other foods so that there's no chance it will drip onto other foods

For information on good food hygiene visit the Food Safety Information Council.



HOW TO READ LABELS

Nutrition information panel

Having an understanding of what's in your food can make it easier to make better choices and look after your transplant. Being able to read a food label will help you choose better products within categories. In particular, pay attention to the energy, saturated fat, sugar and salt content of items you purchase.

When comparing two different products within a category – for example, two different types of yoghurt – always make comparisons using the per 100g column, as serving sizes may be different between the two products.

This link provides an excellent visual reference to understanding a food label.

Health Star Rating system

A food can be rated from 0.5 to 5 stars. The Health Star Rating system is a front-of-pack label to help quickly and easily identify better choices within a food category.

For example: comparing a 2-star cereal with a 5-star cereal. It shouldn't be used to compare a 2-star flavoured drink with a 2-star cereal bar as the nutritional quality, although poor in both, is quite different from each other. The more stars a product has, the better the nutritional quality.

You can find more information at healthstarrating.gov.au

Reading an ingredients list

Ingredients are listed from the highest to the lowest quantity. When buying a product that claims to contain a healthy ingredient, always look to see how high up the list that ingredient is.

Be aware of the many ways sugar can be listed. It may be listed as sugar, glucose, sucrose, fructose, malt extract, rice malt syrup, honey and corn syrup, just to name a few.

Be aware of nutrition claims

Some products will place nutrition claims on their labels. For example, 'salt reduced' does not mean the product is low in salt; it simply means that it has less salt than the original version. Products labelled as 'lite' may not be low or reduced in fat, but light in flavour. Foods with 'no added sugar' may be high in naturally occurring sugar.

For nutrient claims to be made such as 'low in fat' or 'good source of calcium', products must meet certain requirements set out by Food Standards Australia and New Zealand (FSANZ).

Check these claims by referring to the Nutrition Information Panel while choosing healthy foods. For example, products carrying 'low fat' claims may not be low in total energy (kilojoules).

EATING OUT

Take-aways and restaurant foods

When eating out, it can be difficult to find safe and healthy options. Post-transplant, there are certain restaurant foods recipients must be wary of, and this section is designed to help navigate your choices.

Hot foods are safest, while uncooked seafood (sashimi, oysters) and cold cut meats (ham, salami) are risky for transplant recipients.

Sauces and salad dressings containing raw egg products which recipients need to avoid include (but are not limited to) aioli, Caesar salad dressing and hollandaise sauce. Salad dressings can be substituted with lemon juice, balsamic vinegar or pepper; these options also have less calories.

Desserts with uncooked products like raw eggs are risky for recipients and should be avoided. Examples include meringue and tiramisu which contain raw egg whites. Transplant recipients can have cakes, ice cream and fruit-based desserts from the menu instead.

For individualised dietary advice, please speak to your doctor or dietitian.

Fast food

It can be difficult to make healthy choices at a fast food restaurant, as many foods are high in fat, salt and sugar. Some better choices include:

Burgers and wraps: A 'build your own burger' or wrap can be a healthy choice. Choose grilled meat, chicken or fish, cheese and plenty of salad. Try to avoid high-fat meats such as bacon or fried/crumbed chicken, battered fish, fried eggs, or creamy sauces like aioli or mayonnaise. Choose tomato sauce, BBQ sauce, chilli sauce or salsa instead.

It's best to skip chips and nuggets offered with a 'meal deal.' Where possible choose water or a diet soft

Article continues on following page...

drink instead of juice or full-strength soft drinks.

Chicken/ fish and chips: Charcoal chicken can be a healthy takeaway option.



Choose salads with lots of vegetables and fresh salad ingredients. Avoid cream-based potato or pasta salads which are high in calories.

You can also serve charcoal chicken with vegetables such as baked potatoes, pumpkin, carrots, peas, corn and beans, or make a wrap at home using charcoal chicken and extra salad.

Grilled fish is the best option; add fresh salad, and if you have to have chips, share them between family/ friends. Aim for about ¼ of the plate to be fish, ½ salad and about ¼ chips. Limit battered fish and crumbed seafood (like calamari) and potato scallops which are high in calories.

Bakeries and sandwich shops

Choose wholegrain bread, rye bread or a wholemeal wrap. Some bakeries have freshly-made salad sandwiches or rolls which would be a better choice. However, they would not be a healthier option for recipients if they've been pre-prepared and sitting on display.

Add lean protein like chicken, sliced beef, tuna, egg, reduced-fat cheese.

Choose plenty of salads for your fillings like lettuce, tomato, carrot, cucumber, beetroot, onions, chargrilled vegetables and mashed avocado for a creamy spread.

Pies and sausage rolls are very high in fat. **Try to opt for pies with a meat and vegetable filling** like chicken and vegetable; beef tomato & onion or a vegetable pastie.



- ✓ The best options include the '6g of fat or less' sandwich and salad range; wraps and mini subs. Choose fillings such as salad and lean meats (chicken breast, teriyaki chicken, roast beef, turkey) rather than the pizza sub, classic breaded chicken or Italian BMT
- ✓ It's best to skip the cookie and avoid toasties as these do not contain nutritious fillings
- ✓ Best sauces include BBQ sauce, honey mustard, hot chilli sauce, sweet chilli sauce and tomato sauce. Avoid dressings such as ranch/ thousand island and sauces such as chipotle southwest or garlic aioli.

Asian cuisine

Chinese, Thai, Vietnamese, Japanese

Entrees

- ✓ Steamed, not fried. Choose steamed or poached dumplings and fresh rice paper rolls rather than fried entrees such as spring rolls.
- ✓ Soups such as tom yum soup, pho, miso soup, chicken & corn soup, short or long soup are good choices.

Main meals

- ✓ Choose steamed rice and stir-fry-based main dishes that are high in protein. For example: chicken, beef, pork, prawn or fish stir-fry with vegetables and nuts such as almonds or cashews. It's good to include one vegetable-based dish when ordering a few dishes with family and friends.
- ✓ Try to avoid creamy sauces such as satays, coconut milk-based curries or deep-fried dishes such as tempura or katsu-don.
- ✓ Noodle dishes such as pad thai or pad see eew can also be a good choice when paired with vegetables.
- ✓ Reminder: recipients should avoid sushi and sashimi options on Japanese menus.



To ensure your new transplant is stable and reduce the risk of diabetes, obesity and heart disease, it is vital to maintain a healthy lifestyle.

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GIVE THE GIFT OF AN ACTIVE LIFE!



Slouchy Jumper: Soft and light weight cotton jumper. Quoted by many as their "new fave comfy jumper". Perfect for all kinds of weather and occasions. Hip length wide ribbed waist band, round rubbed neck and detailed V-fold cuff on sleeves.

Leggings: Compression fit leggings made from high grade Italian recycled plastic bottle fabric. Two useful pockets on the outer thighs. These tights are a top quality legging suitable for casual walks to high level exercise.



Classic retro street vibe. Our unisex regular fit tracksuit has green and white side stripe details. Wear individually or pair for a complete look.

Details: 4-way stretch polyester spandex.

Features: Full front zip alongside two side zip pockets, fine ribbed cuff, and hem. Woven TX Active logo on chest.

TO FIND OUT MORE AND JOIN OUR CAMPAIGN...

WWW.TXACTIVE.COM.AU

SUPPLIER OF THE AUSTRALIAN TEAM PARADE UNIFORM IN THE 2023 WORLD TRANSPLANT GAMES



Being fit for life makes perfect sense to everyone

You have to work on it every day to make it pay

Fit for Life! is an award-winning initiative which aims to get more transplant recipients more active more often.

Fit for Life! was introduced by the World Transplant Games Federation, proudly supported by Astellas, in 2016 with a long-term goal of improving health outcomes for transplant recipients through moderate, regular physical activity.

The program was developed because studies show that exercise and physical activity is linked to longer survival rates in transplant recipients.

For information on taking part in the next Fit for Life! walk in your state, contact Transplant Australia by emailing contactus@transplant.org.au or follow them on Facebook.

Become and Ambassador

The Fit for Life! Ambassadors are transplant recipients chosen for their attributes of leadership, community-mindedness and inspirational spirit. They volunteer their time to the program to help transition other recipients from a life of sedentary and protective behaviour, to a full and active life post-transplant.

Ambassadors submit applications and are selected by a panel from the World Transplant Games Federation and Transplant Australia.

The current Australian and New Zealand Fit for Life! Ambassadors are:

Kate Phillips, heart double lung recipient (AUS)
Monty Summers, bone marrow recipient (AUS)
Matt Field, kidney recipient (NZ)
Jennifer Dicker, liver recipient (AUS)
Peter Champion, liver recipient (AUS)
Linda Petrovski, kidney recipient (AUS)

Circulator Word Search 2025 list

ABG
ACEINHIBITOR
AIRWAYCLEARANCE
ALLOGRAFT
ANGIOPLASTY
ANTICOAGULANT
AORTA
ARDS
ARRHYTHMIA
ASPIRIN
ASTHMA
ATHEROSCLEROSIS
ATRIUM
BETABLOCKER
BILATERAL
BIOPSY
BNP
BRADYCARDIA
BREATHING
BRONCHIECTASIS
BRONCHOSCOPY
BYPASS
CABG
CARDIACOUTPUT
CARDIOLOGY
CLOPIDOGREL
CMV
COPD
CYANOSIS
CYCLOSPORINE
DEFIBRILLATOR
DIASTOLE
DIURETIC
DONOR
DYSPNEA
ECG
ECHOCARDIOGRAM
EDEMAENDOCARDIUM
EJECTION
EMBOLISM
ENDURANCE
EXERCISETRAINING
FEV1
FIBRILLATION
FVC
HEARTFAILURE
HEARTTRANSPLANT
HEPARIN HLA
HOLTER
HYPERTENSION
HYPOTENSION
IMMUNOSUPPRESSION
INFARCTION
INFECTION
INHALER
ISCHEMIA
ISCHEMIATIME
LUNGTRANSPLANT
MURMUR
MYCOPHENOLATE
MYOCARDIUM
NEBULIZER
NITRATE
NUTRITION
OXYGENATION
PACEMAKER
PERICARDIUM
PHYSIOTHERAPY
PLEURAEFFUSION
PNEUMONIA
PREDNISONE
PULMONARY
PULMONARYFIBROSIS
PULSIOXIMETRY
RECIPIENT
REHABILITATION
REJECTION
RESPMEDICINE
RPE
SARCOIDOSIS
SINGLELUNG
SPIROMETRY
STATIN
STENT
STRENGTH
STROKEVOLUME
SYSTOLE
TACHYCARDIA
TACROLIMUS
THROMBOSIS
TRANSPLANT
TROPONIN
VALVE
VENTILATION
VQSCAN
WALKTTEST
WARFARIN

Circulator Word Search 2025

Can you find all the words listed?

N	S	E	N	O	I	S	N	E	T	R	E	P	Y	H	M	K	A	I	N	O	M	U	E	N	P	A	L	H	X	T
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T	O	A	I	N	U	T	R	I	T	I	O	N	C	A	R	D	I	A	C	O	U	T	P	U	T	F	B	V	T	H
C	N	R	S	E	C	N	A	R	A	E	L	C	Y	A	W	R	I	A	M	E	D	E	A	E	N	P	S	Y	D	Y
E	A	U	O	S	N	E	N	I	C	I	D	E	M	P	S	E	R	S	N	S	I	N	G	L	E	L	U	N	G	C
F	Y	D	R	D	S	U	M	I	L	O	R	C	A	T	V	E	N	T	R	I	C	L	E	V	L	A	V	G	B	A
N	C	N	E	R	X	Z	R	O	T	A	L	L	I	R	B	I	F	E	D	J	T	N	E	I	P	I	C	E	R	R
I	O	E	L	A	I	M	H	T	Y	H	R	R	A	A	N	T	I	C	O	A	G	U	L	A	N	T	R	I	J	D
M	A	I	C	S	T	R	E	N	G	T	H	T	N	A	L	P	S	N	A	R	T	T	R	A	E	H	Z	B	F	I
Y	M	U	S	L	K	N	V	Q	S	C	A	N	O	I	T	A	L	I	T	N	E	V	N	I	T	A	T	S	I	A
C	U	T	O	S	E	U	A	B	S	T	R	O	K	E	V	O	L	U	M	E	D	I	U	R	E	T	I	C	Y	F
O	I	N	R	R	E	R	P	L	E	U	R	A	E	F	F	U	S	I	O	N	A	S	P	I	R	I	N	E	P	K
P	R	A	E	E	T	R	G	M	P	P	U	L	M	O	N	A	R	Y	F	I	B	R	O	S	I	S	X	C	O	D
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T	O	T	G	T	D	R	A	T	Y	I	L	A	U	C	G	A	P	I	H	T	M	T	M	F	R	G	E	T	O	A
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O	D	N	A	B	S	I	Y	A	A	O	I	C	T	D	M	O	L	A	R	O	X	R	A	I	O	R	A	A	B	I
W	R	U	F	B	I	U	A	I	S	L	G	A	I	E	N	I	I	O	N	O	C	T	H	T	E	G	K	I	N	L
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F	O	N	E	B	U	L	I	Z	E	R	P	J	P	N	B	E	L	O	K	E	R	H	T	M	P	R	E	R	R	A
A	H	S	I	S	O	B	M	O	R	H	T	J	G	E	F	U	N	B	R	I	N	A	C	R	H	O	P	E	A	T
R	C	N	Z	A	N	G	I	O	P	L	A	S	T	Y	P	O	N	B	X	I	F	Q	C	M	Y	T	N	E	T	I
I	E	H	Y	P	O	T	E	N	S	I	O	N	I	R	C	Y	C	L	O	S	P	O	R	I	N	E	S	I	E	O
N	O	I	T	C	E	J	E	R	B	R	O	N	C	H	I	E	C	T	A	S	I	S	C	H	E	M	I	A	N	N

Word search solutions on the next page...

IMPORTANT DATE TO REMEMBER

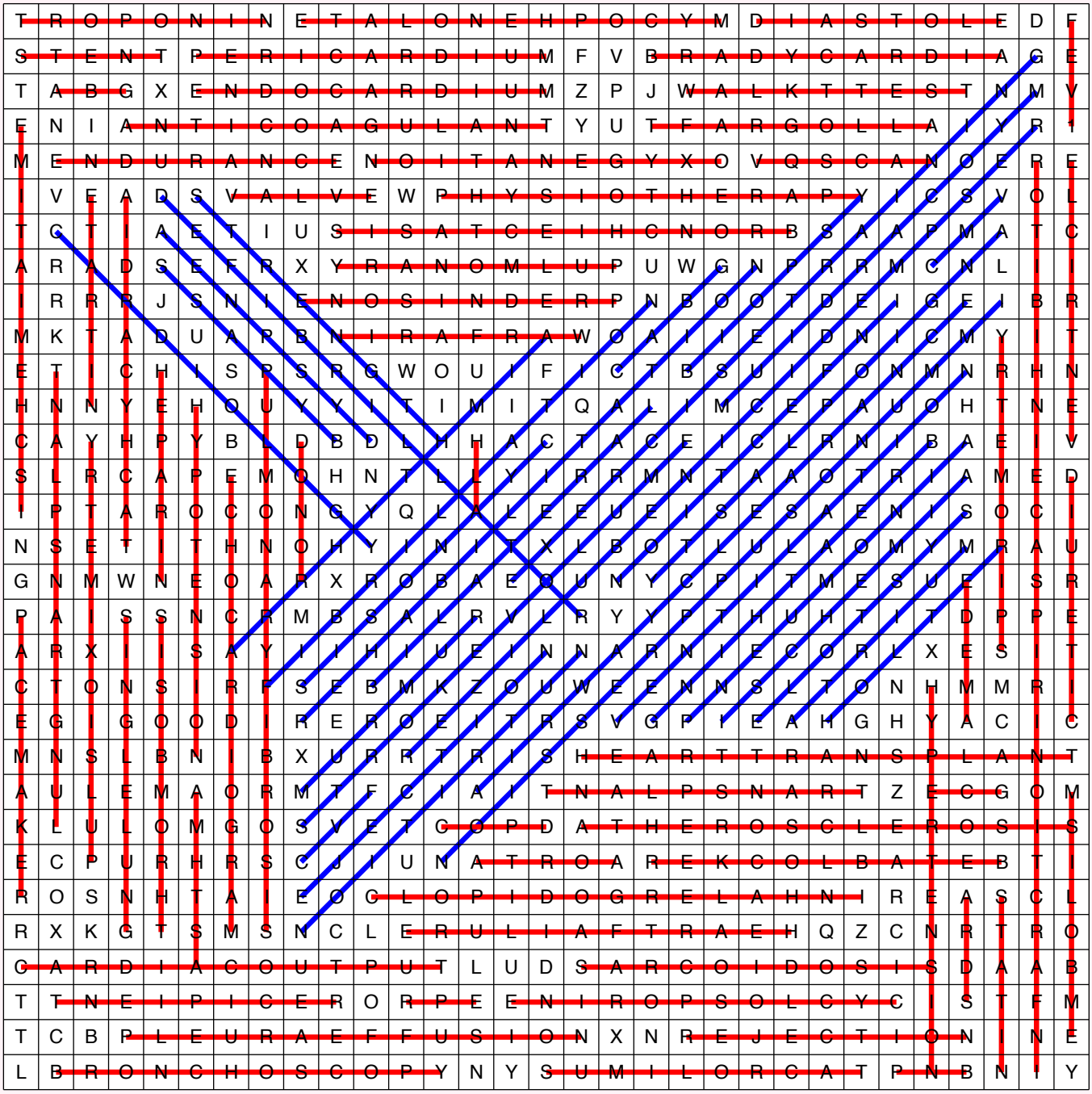
Membership renewal 2025–2026

HLTTV membership fees were due on 1 July 2025 for the 2025–2026 financial year. There are several payment options: cheque, Paypal or EFTPOS and you can renew online. Details available on the HLTTV website:

www.hlttv.org.au/about-us/renew-membership

Your $20 membership fee will greatly assist HLTTV to continue their wonderful work supporting heart and lung transplant patients.

Circulator Word Search 2025 solution



GiveNow

MAKE A SECURE DONATION

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

DID YOU KNOW?

Australia has RECIPROCAL HEALTHCARE ARRANGEMENTS with certain countries which allows you to access basic medical treatment for free. If you're an Australian citizen, this is available to you in the following countries: New Zealand, United Kingdom, Republic of Ireland, Sweden, Netherlands, Finland, Italy, Belgium, Malta, Slovenia and Norway.

For more information visit: www.servicesaustralia.gov.au

Your membership counts

Heart and Lung Transplant Trust (Victoria) Inc

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 ☐

THE CIRCULATOR MAGAZINE

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'* magazine 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 $20 applies to all other categories of membership.

A membership reminder will be included with the annual 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.

HLTTV BANKING DETAILS for making you direct debit deposit when you send or email this form

Name of Account Heart & Lung Transplant Trust (Victoria) Inc | **BSB** 033002 | **Account No.** 415-147

Please return this form to:

Membership Officer, Heart and Lung Transplant Trust (Victoria) Inc
PO Box 25036
Melbourne 3004 Victoria

or email form to: **secretary@hlttv.org.au**

HLTTV

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

REGISTER AS AN ORGAN AND TISSUE DONOR TODAY

DonateLife

DONATELIFE.GOV.AU



BE THE REASON SOMEONE ELSE GETS A SECOND CHANCE AT LIFE

SCAN TO REGISTER

FATHER PHAM RECEIVED A LUNG TRANSPLANT