the Circulator

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

Summer Edition | 2020 | Issue No. 102

CELEBRATING THE LONG TERMERS

In this issue we have a look at some of our long term lung recipients and honour their journeys.

SEE PAGE 12

It's not every day that a 10-year old has their very own transplant surgeon sing them happy birthday ...Cadel Blacker (right) did!

SEE PAGE 4

After a year like no other, let's rejoice that some people got a second chance at life!

President's message

Welcome to Summer! At last in Victoria we've started to see (and feel) some sunshine at the end of what has been a very long and dark 'COVID' tunnel.

Melbourne's hard COVID-19 lockdowns disrupted many of us in many ways, but one thing that stayed constant in 2020 was HLTTV's partnership with the **Park Regis Hotel**. Travel restrictions and border closures in place between Victoria and most other Australian states impacted many rural and regional patients. These restrictions meant that transplant patients and their families required even longer stays at accommodation close to the Alfred Hospital while they awaited surgery or undertook the vital post-surgery rehabilitation program. There was also a lot of pressure on many Melbourne hotels to support different quarantine programs, or to offer accommodation for health care workers concerned about 'taking COVID home' to their families.

I recently had a chat with our *Second Chance Accommodation Program* 'champion', Girish Balwani. Girish provides a friendly face (and voice) for HLTTV enquiries and is a great contact for the Alfred Hospital social work team when they seek support for families who need somewhere to stay. I've been in touch with Girish a lot this year, and I thought sharing part of the 'Park Regis' story would be a nice way to finish the year and highlight this HLTTV partnership.

Belinda: The Park Regis is a valued long-term partner in our *Second Chance Accommodation Program.* How have you and the other Park Regis staff coped during COVID?

Girish: During the harshest restrictions of the COVID period, our team here at Park Regis Griffin Suites were on reduced hours and shifts. It has been a hard, tiring time for everyone, however we continued to make sure there were always enough staff to attend to the needs of our in-house long stay guests, such as those using HLTTV's *Second Chance Accommodation Program*.

Belinda: Early on, the Staywell Group made the decision to remain a 'COVID-free' venue for all stages of Melbourne restrictions. Why did your team make that choice, and why was it important?

Girish: For Park Regis Griffin Suites, we were very conscious of the risks that COVID-19 presented to vulnerable guests, such as immune-suppressed long-stay Alfred transplant patients. That's one of the reasons we made the choice to be a COVID-free venue rather than participate in any of the Hotel Quarantine or 'Hotels for Heroes' programs. The StayWell Group (Management company for Park Regis) also made this choice due to obligations across all the hotels that we manage as well as to protect private residents staying within our properties.

Belinda: The Park Regis always takes wonderful care of HLTTV's *Second Chance Accommodation* guests. These guests would have been especially vulnerable to COVID-19. What sort of things are Park Regis staff doing to help keep all their guests safe?

Girish: At Park Regis Griffin Suites, the health and safety of our valued guests and staff are of utmost importance to us. We monitor the COVID-19 situation with vigilance, and follow stringent guidelines set by the authorities in all areas of our business. We have been independently certified by *Bureau Veritas* and were the first hotel in the Pacific to receive 100% compliance on Safety and Hygiene practices in response to COVID-19. We have precautionary measures in place that include temperature checks for everyone within the hotel, completion of compulsory Travel Declaration forms, two-hourly disinfection and sanitisation of all public areas focussing on high frequency touchpoints, implementation of safe distancing measures and finally, we ensure that masks and hand sanitiser are readily available within the premises.

All of us at HLTTV wish you good health and happiness for the festive season. We're all very much looking forward to a more 'normal' 2021, and especially looking forward to seeing you all 'in real life' at our 2021 events.

Yours in good health,

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

L-R: **Girish Balwani** (Park Regis, Manager), **Cadel Blacker** and mum **Kristy Blacker.** Cadel is ten years old and travelled from Queensland for his double lung transplant at the Alfred recently. Kristy was a guest of the Park Regis during Cadel's seven-week hospital stay and both are there now during his rehabilitation program. **Read about Cadel's journey on pages 4 – 7 in this issue of the Circulator.**

Secretary's message

The end of 2020 is in sight! Christmas, summer and plans for a New Year are lifting the spirits after such a crazy year.

Personally, I have reflected on 2020 with mixed feelings, but focusing on the positive has kept us going.

We've been walking for coffee with the dog, I've read so many more books, made lots of lemony things after raiding friends' lemon trees, developed a new sense of local community with our lovely neighbours whilst sharing our plants, baked and brewed, Zoomed some trivia nights and online family dinners eventually culminating in a COVID-safe birthday picnic with rotating guests.

A huge THANK YOU to my generous friends who donated to my *Big 50 + 10 years* birthday fundraiser for HLTTV which warmed my heart.

The HLTTV Committee held its Annual General Meeting via Zoom and elected eight members. You can find the Committee members' contact details to the right. There is plenty of room for anyone else interested in joining the Committee, developing the organisation and planning COVID-Safe activities for 2021.

Give any of us a call and have a chat about how you could be involved.

Looking forward to a happy, healthy and fun 2021.

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

Season's
GREETINGS

The Lungitude Foundation is a registered Australian charity focused on funding and facilitating world-class translational research, advocating for lung transplant excellence, building a strong community of support, and educating key audiences.

We invite you to take a look at our latest Impact Report below...

You can view the Impact Report at www.lungitude.com.au/our-impact/ where you have two digital options – computer or smartphone

Heart to Heart House, Barmah Vic

...a great place to relax

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The spirit of the battler

When his parents named him, little did they know the meaning of his Welsh name would truly define the fight in their son's personality.

Written by Kristy Blacker, this feature tells the story of a mother and son, hundreds of kilometres away from home, in an unfamiliar city in a different state in the middle of a global pandemic. It is an inspirational story about a young man who has been given a second chance at life and a mum who went to great lengths to make sure he got that chance. Editor

The name Cadel has the meaning of 'spirit of the battle' and Cadel is the name of the third child for my husband Scott and myself.

We already had a daughter Lorelei and a son Xavier and we always spent a lot of time when choosing a name for our children. Scott (my husband) and I have both always admired Cadel Evans, the Australian cyclist, but when we chose the name for our third child, little did we know what was ahead for him and that his name's meaning would ring true for him so much.

My name is Kristy and my son Cadel had a double lung transplant in October 2020.

Cadel was born in 2010 in a hurry and was sick from the very start. At just five weeks of age he was diagnosed with Cystic Fibrosis.

Cystic Fibrosis, or CF, is a chronic illness that primarily affects the lungs and digestive system as they get blocked up with a thick sticky mucus.

Cadel had a lot of respiratory infections at a young age despite our best efforts to keep him as healthy as we could. When Cadel was just two years of age Scott and I were sat down and told the devastating news that Cadel may not make it to the age of three as his lungs were so scarred from repeated respiratory infections.

We are glad to say that Cadel celebrated his third birthday as well as many more, due to our family's dedication to his health, having a positive attitude for his future and the backing of an amazing CF team at the Queensland Children's Hospital (QCH).

Cadel has continued to spend a lot of time in hospital having regular admissions for IV antibiotics to fight off infections in his lungs.

In December 2019 Cadel was admitted again for another round of IV antibiotics and he became very unwell. During this admission the team in QCH decided it was time to engage the paediatric lung transplant team in Melbourne as Cadel was running out of options.

This was of course a hard time for our family again but we took the same attitude that we had in the past that we would do anything for more time with our child.

In late February 2020 the process for the transplant was started and in early March some of the transplant team flew up to Brisbane to meet Scott, myself and Cadel to discuss the transplant options.

Cadel all loaded up for his transfer to the Alfred Hospital in Melbourne

They explained that the Alfred Hospital in Melbourne was the only place in the nation to perform paediatric lung transplants so when the time came for Cadel's transplant to happen he would need to be transferred to Melbourne.

Little did any of us know that a global pandemic was starting!

The transplant process became delayed and our trip to Melbourne to complete the necessary assessments was postponed as the nation, and the world, went into lock-down.

We were all concerned how this delay would impact Cadel's health.

In early June the Alfred lung transplant team contacted us and the process resumed as the world adapted to a new normal.

We started the assessments and transplant process again, but this time via zoom and telehealth calls. It was a lengthy process over two separate days and included hours of video calls with a number of health professionals.

Cadel was officially listed on the double lung transplant list in July this year and it was decided that we could wait for the call while continuing to live in Brisbane as Cadel's health was stable.

We carried on about our days, with school and work, while waiting for the all-important call and then in October Cadel became unwell and ended up in intensive care in the QCH on hi-flow oxygen.

Both the QCH and Alfred teams were concerned about the sudden change and decline in Cadel's health and made the decision that he needed to be medically transferred to Melbourne to wait for donor lungs. This opened up more options to available organs as his need for transplantation became more urgent.

The transfer happened very quickly,. Once the decision was made it was literally two days later that we waved goodbye to the family, and Brisbane, with no idea when we would be returning. We were very unsure how this would all play out as Cadel was extremely unwell.

It wasn't as simple as just jumping on a plane either, as Cadel was so unwell he required hi- flow oxygen and constant monitoring.

LifeFlight Australia jumped into action as they were tasked to fly us down to Melbourne in one of their jets.

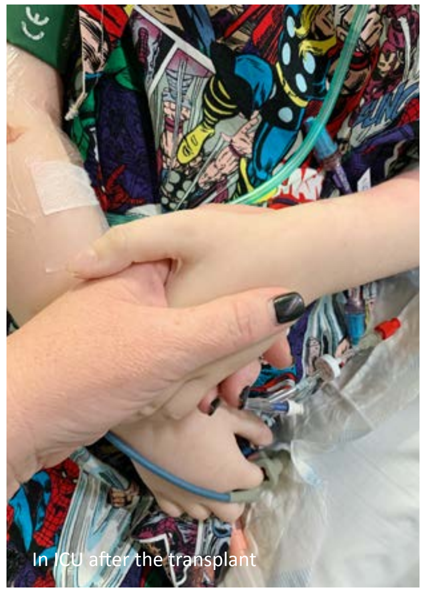
As Melbourne was in major lock-down due to a second wave of COVID-19 we were only allowed to have one parent accompany Cadel. We had to get permission from the Queensland chief medical officer and both have two negative COVID-19 swabs before we were cleared to fly.

I flew down with Cadel, not knowing when I would see Scott, Lorelei and Xavier again. It was also unclear how long we would have to wait in an unfamiliar city before suitable lungs became available for Cadel.

Cadel was admitted to the Melbourne Royal Children's Hospital to wait and continue being treated for his declining health.

One evening a Doctor asked me to have a seat in a meeting room and I had a horrible feeling of doom. No good news generally happens in these sort of rooms. Well that was about to change.

The doctor advised me they had found a match for Cadel and he would be getting new lungs!


In ICU after the transplant

This was both exciting and scary and I couldn't help but think of the devastating time for the donor family.

I immediately left the room to call Scott and share the news. We Face-timed to tell Cadel together that he was getting a second chance at life! Cadel, like us, shared those feelings of excitement and fear.

The transfer to the Alfred happened early the next morning and Cadel was prepared for surgery. Again we made last minute video calls to family before the surgery to say *"see you soon"* and wish him luck.

It was a worrying time but we knew he was with the best-of-the-best and so we handed our little man over to them so they could give him the greatest gift ever.

The wait to hear if the surgery went well and he was in ICU felt like it took forever. I was alone in a strange city, Scott was at work back in Queensland with our other children who were at school, but we were all worrying about what was happening and waiting for the news that he was out of surgery.

That call came thankfully and the surgery was completed without complication.

Seeing Cadel in ICU is a sight I will never forget and I did it alone, with no other family by my side to comfort me. It was truly a very trying and emotional time.

The period in ICU was challenging – seeing Cadel, so little in this big bed, with tubes and lines everywhere.

It was very tough for Scott to be back in Queensland and only able to share the moment over Face-time, and unable to hug and reassure us that everything was OK.

Cadel spent a considerable amount of time in ICU and experienced a few complications including a re-intubation. The doctors and staff, however, were happy with his progress.

Borders were still closed during this time and lock-downs were still in place due to COVID-19 restrictions.

I missed the rest of the family terribly and they missed us too. It was really hard to be away from them during a time when you are normally comforted by family. It definitely was an emotional roller-coaster.


Getting better and having some time outside while still in ICU

Things change so quickly in an ICU environment. It was draining emotionally and physically and when I tried to sleep I was worried about how Cadel was coping overnight, all alone in an adult hospital with the 24/7 buzz and rumble of an ICU. Add to this the need to try and keep our family in the loop with everything going on.

Cadel did really well with his recovery from surgery and in no time was transferred to the ward – just in time to celebrate his 10th birthday in nearby Fawkner Park.

The lovely and amazing staff of the Alfred rallied around Cadel and myself and organised a party in the park across the road from the hospital with a fantastic cake and even sang happy birthday to him.

It was a bitter sweet moment as there were times when we weren't sure he would make it this far.

Cadel was well enough to leave the hospital grounds for the first time, he was turning double digits and had a second chance at life, but our family was back in Brisbane and not able to be here to celebrate all these amazing milestones.

I must say though, it was pretty special to celebrate with Dr Julian Gooi, the surgeon who gave him a second chance as well as the other staff who worked so hard to make the transplant a possibility and help Cadel with his recovery.

Cadel kept amazing the doctors and staff with his recovery and was discharged to an apartment as part of the *hospital-in-the-home* (HITH) service.

Cadel was technically still an inpatient, but the nurses came to him twice daily to administer IV antibiotics. This was amazing as it was the first time in months he wasn't in a hospital bed and had some freedom to be a normal ten year old.


Cadel's birthday party in the park with some of his Alfred Hospital medical team – including his transplant surgeon, Dr Julian Gooi


Finally discharged

Things continued to go smoothly and Cadel soon finished the round of antibiotics and is now officially discharged from the Alfred and attending appointments as an outpatient.

He has medical reviews, check-ups with an occupational therapist, psychologist, dietician, physio's and has regular blood tests. He will continue to do this until mid-January when, hopefully, he will be cleared to fly home to Queensland in time to start the new school year where he will begin Year 5.

During Cadel's admission to the Alfred and then during his rehabilitation as an outpatient, we were lucky enough to have the support of the *Heart & Lung Transplant Trust of Victoria* (HLTTV) to have accommodation close to the Alfred. Staying at the *Park Regis Griffin Suites* (see article on page 8) on St Kilda Road was a massive game changer for us as the financial cost of staying near the Alfred for such a long time would have been extremely difficult for our family.

I will be forever grateful to the HLTTV to have had somewhere close to the Alfred during the period when Cadel was in ICU as I was staying by his side at the hospital for very long days (many over 13 hours) and then heading back to the accommodation to cook dinner, make some lunch for the next day, have a shower and try and get some sleep.

It was a welcome escape from the beeping machines and busy routine of ICU and when Cadel was admitted to the ward it was a place to wash clothes and refresh and prepare for the next day.

During HITH it was a place close enough for the nurses to visit twice daily to administer IV antibiotics and, as an outpatient, a home away from home for Cadel and me.

We are able to have local adventures on weekends, sightseeing and ticking a few previous *'The Block'* TV show building sites off our list as we are big fans. We walk to his regular visits to the hospital which is sometimes three times or more a week at the moment.

It will also soon be a base for the rest of the family to visit and reunite to spend Christmas together and explore a new city.

Our family is forever thankful to the donor and their family for their 'gift' in a devastating time of loss and grief. We will always remember them as we celebrate all Cadel's milestones – big and small – and continue to create many new memories to treasure.

He has seen it all

Professor Greg Snell was there at The Alfred from the beginning when Trevor Williams and Don Esmore performed the first lung transplant in 1990. He left to study overseas and returned in 1992 and is still there.

by Circulator Editor, Graeme Klemm

Q&A

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

Professor Greg Snell MBBS FRACP MD OAM is currently the Medical Head of the Lung Transplant Service at the Alfred Hospital and Monash University.

After completing his initial medical training at University of Melbourne, he completed the Will Rogers Clinical Fellowship in Lung Transplantation at the University of Toronto, Canada in 1992.

He has been involved in the implementation of new techniques and technologies in lung transplantation, in particular the use of Donation-after-circulatory-death (DCD) lungs.

PHOTO: MARK TAYLOR/STUFF

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

In this edition of Q&A you meet another of those well known faces at The Alfred – particularly if you have been a patient suffering from all manner of respiratory illnesses – Professor Greg Snell.

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

Towards the end of school I met up with a family friend who was a medical specialist and he showed that medicine was a science career with lots of different directions and options.

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

I actually started off being interested in cardiology, but when I worked as a junior doctor I discovered that the heart was actually nowhere near as interesting as the lung, and so I headed that way.

You completed a 'Will Rogers Clinical Fellowship in Lung Transplantation' at the University of Toronto, Canada in 1992. Can you briefly outline some similarities and differences between the Australian and Canadian health systems as they relate to respiratory illnesses and transplantation.

The biggest difference between our system and the Canadian (and American) system I saw was how involved and passionate our Australian staff were compared to their North American colleagues. Our staff take our their jobs more 'to heart' and work harder to get everyone the best results possible.

Can you briefly outline the pathway that brought you to The Alfred?

I trained as a lung specialist at the Repat Hospital in Heidelberg, but an extra six months was required so I took a 12 month job in Respiratory at The Alfred. This was in 1990 and the first lung transplant, organised by Trevor Williams and Don Esmore, took place 2 months later. I found this amazing and the next year I went off to study lung transplant in Toronto – the group who had done the world's first few years before. I came back in 1992 and stayed since.

You present many papers, both locally and internationally, is there one in particular that has resonated with your professional audience?

Yes, our paper in the *American Journal of Transplantation* on how to increase lung transplant numbers by using donation after circulatory death (DCD) lung donors (ie when the heart stops, rather than the brain) has changed the world, with thousands of cases across the world now done using this technique.

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

I have certainly seen some amazing people with incredible courage and miraculous recoveries. I am forever humbled by looking after people who survive and flourish in tough situations that I don't think I could handle myself.

Outside your clinical work do you pursue any particular leisure activities to unwind?

Walking, swimming and if the opportunity arises skiing or sailing.

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

Some of the funny stories that people come up with about their lives and medical adventures – particularly when they deliberately or accidentally mispronounce the name of a medicine (eg Lasix = Latex, Pseudonomas = Sodomonas)

What are you thoughts on the future treatment of CF? Are their any exciting innovations on the horizon that may assist patients with this condition?

The new CF gene modulator drugs are amazing and will change the lives of the whole CF population from now on.

Reference: www.kidney.org/transplantation/transaction/TC/winter14/What_You_Need_to_Know_PostTx

The forbidden fruits

Grapefruit and certain other citrus fruits, such as Seville oranges, can interfere with several kinds of prescription medications. Don't take these interactions lightly – some can cause potentially dangerous health issues.

Fruits and vegetables are healthy dietary choices for most people. As common "healthy" staples on many plates, it is easy to forget that certain fruits and vegetables can interact with transplant medications. Some herbal products may also have similar interactions.

Why do certain foods cause interactions?

These interactions are usually due to either the natural ability of the food to activate the body (even in ways that can be similar to medications) or as a result of drug-food interactions with medications. For transplant recipients, the most frequent interactions are those that activate the immune system and those that affect the ability of the drug to enter or exit the blood. As a result, some foods and herbal products are no longer safe to consume after receiving a transplant.

What foods should I avoid after receiving a transplant?

The following fruits and juices may interact with your immunosuppression, causing toxicity. They should be avoided.

- Grapefruit and grapefruit juice (please note that some citrus-flavoured drinks have a grapefruit extract in them, so it is important to check ingredient lists.)
- Pomegranate and pomegranate juice
- Seville Oranges (normal oranges are fine in moderation)

Other fruits and vegetables that should be consumed in moderation are grapes, cranberries, tangerines, cauliflower, and broccoli.[1]

What supplements or herbal products should I avoid after receiving a transplant?

Many supplements and herbal products have drug interactions with your immunosuppression or may increase the risk of toxicity or rejection. Please talk to your transplant doctor or pharmacist before starting any new supplements or herbal products.

Some of the more popular herbal products that can have adverse interactions include:[2]

- Vitamin C
- St. John's Wort
- Herbal teas: green tea, chamomile, peppermint, dandelion
- Echinacea
- Ginseng
- Feverfew

Living with a transplant requires achieving a balance between having enough of a natural defence system to protect from everyday sicknesses such as a cold or the flu and lowering the immune system enough to protect the transplant from being attacked and rejected by the body. **Please talk to your doctor or pharmacist if you have any questions about what foods, medications, or herbal supplements are safe to use after transplant.**

1. Rodríguez-Fragoso L, et.al. Potential risks resulting from fruit/vegetable-drug interactions: effects on drug-metabolizing enzymes and drug transporters. J Food Sci. 2011 May;76(4):R112-24. doi: 10.1111/j.1750-3841.2011.02155.x. Review. PubMed PMID: 22417366.
2. Moore LW. Food, food components, and botanicals affecting drug metabolism in transplantation. J Ren Nutr. 2013 May;23(3):e71-3. doi: 10.1053/j.jrn.2013.02.002. PubMed PMID: 23611558.

LUNGITUDE FOUNDATION'S
2020 LUNG TRANSPLANT RESEARCH PRESENTATION

Watch a replay of
LUNGITUDE'S
LUNG TRANSPLANT
RESEARCH PRESENTATION
for 2020.

Hear directly from world-class researchers and specialists
(including Alfred lung surgeon Prof Greg Snell)

https://www.lungitude.com.au/event-gallery/

For the love of pets

I am Sophie
Breed: Golden Retriever
Partner: Adam Szmulewicz
Social Worker and Dog Therapy

My name is Adam Szmulewicz and my K9 friend Sophie and I are a dog therapy team at Alfred Health. I work as a social worker at the St Kilda Road Clinic (SKRC) which is an out-patient mental health clinic.

We visit the medical wards at the Alfred Hospital as well as the sub-acute mental health residential units.

Sophie's career at Alfred Health began at the beginning of the COVID-19 outbreak. Sophie was initially requested by management to attend SKRC to boost staff morale. The word got around quickly, and Sophie and I are now very busy sharing her unique and gentle love, the fundamentals of dog therapy, which staff and patients equally enjoy.

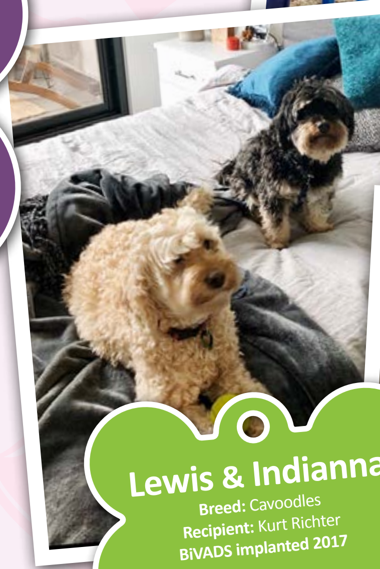
The feedback I get, typically, are comments on how relaxed people feel as they engage and interact with Sophie through pats. Patients and staff also consistently say that a pat and a cuddle with Sophie has *"made their day"*.

Her gentle, social nature and desire to walk up to everyone in the room for pats and cuddles is testimony to the unconditional love offered by dogs which is the central tenet of a healthy post transplant recovery alongside a pet.

Nurses at the Alfred Hospital show Sophie some love during one of her visits

Pets are renowned for their unconditional love and affection, especially when we may have some emotional or physical challenges. This has been especially true after transplant for many people. Like other aspects of life after transplant though, hygiene considerations need to be taken.

I am Max
Breed: Alusky
Recipient: Kaitlyn Morris
Heart transplant 2019



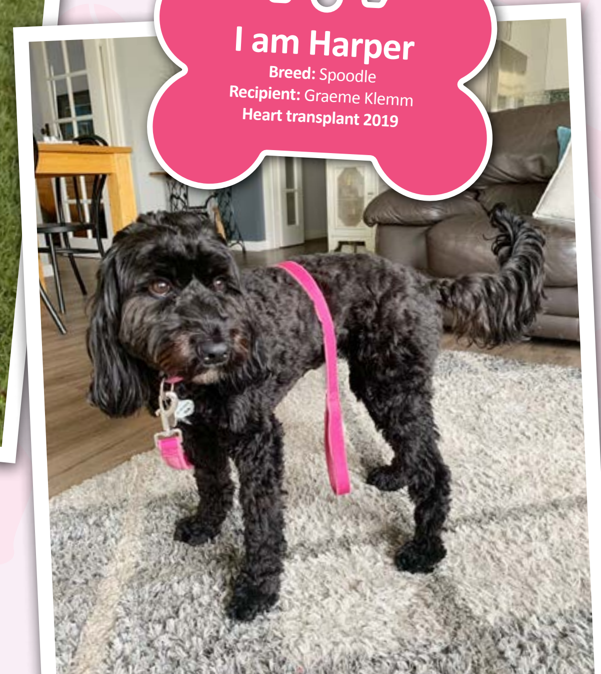
Lewis & Indianna
Breed: Cavoodles
Recipient: Kurt Richter
BiVADS implanted 2017

I am Hercules
Breed: Yorkshire Terrier
Recipient: Kirsten Larsen
Single lung transplant 2003

I am Louie
Breed: Beagle
Recipient: Nicole Constantinou
Heart transplant 2018

I am Pablo
Breed: Greyhound (adopted)
Recipient: Karen Pritchard
Lung transplant 2015

I am Murray
Breed: Border Collie
Recipient: Gordon Miller
Heart transplant 2018



I am Harper
Breed: Spoodle
Recipient: Graeme Klemm
Heart transplant 2019

IN IT FOR THE lung haul PART 2

In this second look at our 'long termers' we celebrate the incredible long-term anniversaries of some very grateful lung transplant recipients. Transplantation gives a second chance at life so recipients and their loved ones have a great deal to celebrate. And of course every single one of them gives generous thanks to their donor and the wonderful staff at The Alfred. *Long live the 'lungies'.*

27 YEARS

Jane Fletcher

Lives: Chadstone (VIC)
Transplanted: October 1993 Bilaterial sequential lung
Surgeon: Prof Don Esmore
Thoughts: Transplant has given me opportunities to live a full and rich life. Certainly not without its complications, but definitely rich and full. I've been able to complete postgraduate studies in psychology and work full time in my own practice as a health psychologist with cancer and palliative care patients. I know everything I have been through has made me able to do the work I do. I've travelled extensively and most of all have had a lot of fun. I have an amazing partner and support network around me: Jane's Ocean – Individually we are one drop, together we are an ocean. My attitude to life is simple – stay in the now, control what you can, and keep filling the joy cup.

21 YEARS

Vaness Scott

Lives: Emerald (VIC)
Transplanted: June 1999 LL
Surgeons: Dr Adrian Pick and Dr Julian Smith
Thoughts: 6 months after I had my transplant, I returned to work full-time and haven't looked back. I now work as a Product Owner in the Dept of Premier and Cabinet, Victoria. Since my transplant I was married, became godmother to three beautiful girls, travelled overseas with mum twice and went on a cruise to the South Pacific. Last year my husband and I bought a camper trailer and went on a 6-week, 6000km outback trip to the *Big Red Bash* in Birdsville - the world's biggest music festival in the middle of the Simpson Desert - as well as outback NSW, Qld, & SA.

18 YEARS

Len Hain

Lives: Caulfield South (VIC)
Transplanted: November 2002 LL
Surgeon: Prof Silvana Marasco and Dr Marc Rabinov
Thoughts: I still reflect on my good fortune, not only for my 're-birth', but enhanced and made possible by the expertise and attention I am receiving in many cases from the same medical staff who got me 'over the line' 18 years ago. I enjoy the pleasure of having seen our two children grow, settle, and present us with four grandchildren. My voluntary work with *DonateLife,* social activities with fellow transplant buddies, and still running my own business at 80 years of age are all things that my wife and I are truly grateful for.

18 YEARS

Nikola Radocaj

Lives: Melbourne (VIC)
Transplanted: November 2002 LL
Surgeon: Dr Michael Rolland and Dr Adrian Pick
Thoughts: In the 18 years since my transplant, I have been blessed to see my three children grow up, graduate university, and 10 years ago, see the arrival of a grandchild. With my wife, I have been able to visit family in Europe and my country of birth, Croatia, as well as travelling in Victoria, NSW, Qld and SA with friends. Apart from spending time with family, the greatest joys of my life include tending to my vegetable garden, and continuing family traditions including making wine, growing fruit, making smoked sausages and prosciutto, and spending time outdoors.

18 YEARS

Sarah Quinn-Pagett

Lives: Perth (WA)
Transplanted: May 2002, Double lung for Cystic Fibrosis
Surgeon: Prof Don Esmoree
Thoughts: Where do I begin... I had to relocated to Melbourne for my transplant back in 2002 due to Perth not having a transplant unit at that stage. I was only 17 when I was transplanted. I became a teacher and have adored my career for the past 13 years. I met and married the most amazing man and we have two gorgeous sons, a 4 year old and a newborn 9 weeks.

17 YEARS

Kirsten Larsen

Lives: Aspendale Gardens (VIC)
Transplanted: February 2003 L
Surgeon: Prof Trevor Williams
Thoughts: Since the transplant I have found myself a lovely partner Les. We have been travelling all over Australia. Normally we spend the best part of winter up north in our motorhome with our little dog Hercules. When we're home in Victoria I plod around in my little green house and grow fresh produce. I also find to time to run a class making handmade cards in the village in which we live.

donatelife

The importance of registration and family discussion

9/10 families gave consent for donation when their family member was a registered donor

7/10 families gave consent for donation when their family member wanted to donate

6/10 families gave consent for donation when their family member was not registered and had not discussed donation

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A DAY IN THE LIFE OF A Donation Specialist Nursing Coordinator (DSNC)

Each year thousands of Australian lives are saved and transformed through the generosity of organ and tissue donors and their families.

While the majority of Australians believe it's important to be an organ and tissue donor, only one in three are registered. *DonateLife* Victoria encourages more Australians to register to be an organ and tissue donor, and to have a chat about it with their family and friends.

In this edition, we speak to Indra Gramnea who has been a Donation Specialist Nursing Coordinator with *DonateLife* Victoria since 2017. Indra talks about her unique role, working hand-in-hand with donor families during their time of grief.

Why did you start working as a Donation Specialist Nursing Coordinator?

Having worked as an emergency nurse for many years, I cared for many patients and their families during very devasting times in their lives.

I always valued the time I spent with families at the bedside and being able to provide the best end-of-life care for my patients.

Working as a Donation Specialist Nursing Coordinator has allowed me to continue to care for patients and their families and offer them something positive through the gift of donation at a time of sadness and loss.

Indra Gramnea (DSNC)

KEY MESSAGES

- **Register to become an organ donor at donatelife.gov.au**
- **It takes less than a minute, you just need your *Medicare* card**
- **Tell your family and friends that you want to be an organ donor.**

Please take us through a typical week at work...

There isn't really a typical week in my role because of the spontaneous and diverse nature of my job, but usually a week at work would comprise taking referrals, discussing organ and tissue donation with families of patients who are at end-of-life care, coordinating donation cases and completing hospital-based work, which may include conducting education sessions for staff, portfolio work, and auditing.

What do you enjoy about your role?

What I enjoy most about my role is coming to work every day and making a difference to the lives of others. It is a privilege to come to work every day and meet so many amazing, generous families who think of others at such a challenging time in their lives.

What would you say to other people thinking about entering this stream of nursing?

The role I work in is extremely rewarding. It is such a nice feeling to be able to go to work every day and advocate for patient's wishes and know that there are people who will receive life-saving transplants as a result of generous organ donors, their families, and our work.

Are there any myths about organ and tissue donation you would like to dispel?

One myth I've heard from people is that once you've registered to be an organ and tissue donor you don't need to discuss it with your family. The truth is that it is very important that people discuss their decision about organ and tissue donation with their families because your family plays a crucial role in the donation process and supporting the decision to be an organ donor.

It takes less than a minute to join the *Australian Organ Donor Register* (or to check your registration) at donatelife.gov.au. All you need is your *Medicare* card or register by calling 1800 777 203.

donatelife

Let's talk organ and tissue donation

A new podcast from DonateLife – coming 2021

Wellbeing across the holiday period

Karen Linehan
Health Psychologist
B. Psych (Hons.) M. Psych (Health)
MAPS, MACRSA

Karen has been a registered Psychologist since 2011, completed a Masters in Psychology (Health) at the University of Adelaide in 2014 and has worked within the heart failure service across the central Adelaide Hospital network for the past 5 years. She has a private practice aimed at supporting individuals and their loved ones with chronic health conditions.

As we approach the end of an incredibly challenging year with Christmas and the holiday season upon us, it is important to consider ways to enhance or to manage your wellbeing.

While for a lot of people the end of a year signals a time for celebration, for others, it will be a time of continued medical appointments, loss of loved ones or anniversaries of past losses, waiting for treatment or transplant, closure of usual rehabilitation programs as well as potential isolation.

Hence pre-planning or thinking about ways to manage your wellbeing for this upcoming period is essential to being able to avoid heightened emotional distress, isolation, depression, anxiety and in turn adverse health outcomes or re-hospitalizations. Below are my top 6 tips from my experience as a Health Psychologist to enhance or help manage your wellbeing over the coming weeks.

It's important to note that there are many methods to do this and effectiveness will vary from person to person, depending on many factors. My aim is to share with you what patients and their loved ones have said they have tried and found to be helpful and hopefully they will be for you too.

1. **Considered where your current wellbeing is at** on a scale from 1 to 10, where 10 = highest level of wellbeing and 1= lowest level of wellbeing. Ask yourself why is my wellbeing at this level? What can I do to maintain this level of wellbeing? What can I do to improve my current level of wellbeing? What has helped (strategies, resources, people etc.) in the past to improve my wellbeing and how can I activate these things now? Identify someone you know who has a high level of wellbeing and consider what do they do, think, or feel that might help them to have that level of wellbeing?

Wellbeing: A state of happiness and contentment, with low levels of distress, overall good physical and mental health and outlook, or good quality of life.

American Psychological Association, 2020

2. **Implementing strategies to improve your wellbeing, such as:**
   - **Tackle issues with Sleep:**
     - Keep a sleep diary to identify any trends or patterns to sleep disruption to understand where to start to improve your sleep to then discuss with your GP and/or Psychologist.
     - Establish a deliberate sleep routine; consider the time that you go to bed and get up as well as aim to keep this as consistent as much as possible. Consider what you eat and drink prior to bed – limit caffeine and heavy meals. Reduce the use of blue screens (such as iPads and smart phones) immediately prior to going to bed.
     - Associate bed for sleeping and sex rather than a time to think and worry. If you notice you spend time worrying when you go to bed, have a notebook by your bed to write any worries down and then put this aside and remind yourself that you have given your concerns some airtime to the worries and that bedtime is for sleeping. Listen to relaxing music to distract the mind from worries.
     - If you are in bed and have not fallen asleep within 20 minutes, get up and do some low-level activity (such as reading, stretching, washing your face etc.) and reattempt going back to sleep after this (repeat to ensure that the brain relates bed to sleeping and not to being awake time).
     - Consider environmental factors that may promote good sleep, such as appropriate room temperature, lighting, pillow comfort, smells etc.
3. **Practice employing a 'Wise-Mind'.** This concept was created by Dr Marsha Linehan as a core skill of *Dialectical Behaviour Therapy* (DBT) that can assist individuals with tolerating distress. As you can see from this depiction, Dr Linehan described three mind states; **Reasonable Mind** (logical and fact/evidenced based), **Emotional Mind** (passionate, reactive, impulsive) and **Wise Mind** (the synthesis of rational and emotional mind).

Figure accessed from: www.drivingpeace.com/wise-mind-soothe-anxiety/ December 2020

Wise Mind allows us time to consider the facts and the emotions in each situation, to take a breath or a pause and for you to be able to provide a balanced response to a person or event. In turn employing a wise-mind helps to reduce distress relating to events and/or decisions while promoting mindfulness and being grounded in the moment (Linehan, 1993).

Figure accessed from: https://5waystowellbeing.org.au/about-wellbeing/ December 2020

4. **Consider practising the 5 Ways to Wellbeing:**
   - **Connect:** With positive people and socialise where you feel you can.
   - **Be Active:** Continue where possible to sustain the movement or exercise plan you have with your exercise physiology team. Remember to pace yourself to avoid burn out and fatigue.
   - **Keep learning:** The adult brain is capable of learning and re-wiring itself. If you have time to yourself, consider a lea bring a new skill or doing a course, or activity that you would like to try.
   - **Be Aware:** Take time to pause and notice your surroundings and focus on the moment, noticing your thoughts and feelings without getting lost in them.
   - **Help others:** Evidence shows that helping others can help our own sense of achievement, happiness, and overall wellbeing. A smallest hand to help can make the biggest of differences to others and to ourselves.
5. While the end of the year often brings a time for pause and reflection which can be beneficial, it may also be important to consider and propose **a personal Theme or Mantra** for the next 12 months. These are best developed by thinking about what is important to you, **what you value** and thinking about how a theme or mantra might help keep you living life towards this value and help to realign back to this way of living, if there is a setback. Examples of themes might be *"Self-Care", "Self-compassion"* and Mantra might be *"I am stronger than my fears", "I deserve to be happy".*
6. Remember speaking to someone whether it is a friend, family member, counsellor or psychologist is a great way to unload stress and to build or to maintain your wellbeing.

There are also helplines available to speak to someone at any time:

Lifeline	**131 11 14**
Suicide Call Back Service	**1300 659 467**
Beyond Blue	**1300 224 636**
1800 Respect (Domestic Violence)	**1800 737 732**
Mensline	**1300 789 978**
Kids Help Line (<25 years old)	**1800 551 800**
Headspace (<25 years old)	**1800 650 890**

Faith

Circa 2008/2009 while living in my house of three decades in Prahran East, I'd often notice this gorgeous young woman renting a little cottage two doors away, often walking her two dogs, or getting into her car.

I guessed she might have been a dancer or the like because of her carriage, and how she moved. A striking brunette, she was delightful to watch but I'd never had the chance to meet her.

Then she seemed to vanish for a short time. When she returned and I spotted her one day, I introduced myself and discovered much in those first few minutes of conversation.

She had been back in Adelaide, her home town, but was in Melbourne to pursue her career as a singer, and to study dance.

I had guessed right. I also discovered that she was about to be admitted to the Alfred Hospital for on-going treatment for cystic fibrosis.

I remember being bowled over that such an active, vibrant woman suffered from such a debilitating disease, and yet clearly refused to be defined by it. Later in the day I found myself thinking of this beautiful young woman, and so went off and bought some flowers.

When I arrived at the Alfred, the nurses on her ward couldn't locate her, so I left the flowers on her bed with an accompanying note.

That was the beginning of a deep friendship between a woman in her 60s and another in her 30s. Our paths would never have crossed had she chosen to rent on another street in Melbourne, but life brought us together and for that I'll be forever grateful.

Back in Adelaide now, my precious friend lost her beloved mother recently. Gone far too soon at around the same age as me. I know her mum had thought of me as a surrogate mother for her daughter from the time of our first meeting, but little did we imagine that I would ever need to step into her shoes.

Our meeting as neighbours, in the scheme of things, wasn't that long ago, and yet it feels as though it has always been. At my lowest times when I grieve for my son who died as a baby 30 years ago, it's this friend, of the same generation as he, who gets it, perhaps more than many.

Upon reflection, as I navigate the autumn of my life, I've come to a deep realisation that faith for me is essentially about humanity at its best; simply, kindness to each other and loyal friendship, new and old, that give my life meaning.

By Janine Joseph
Janine is a well known Melbourne writer

This story has previously been published in *The Sunday Age*.

Team Jones setting an example

You may or may not be a 'goal' setter in your life, but getting to and getting past a transplant requires a positive mindset to look forward.

Having been an avid lawn bowler for over 20 years, Glen Jones from Millicent in South Australia was mortified when his health took a turn for the worst in late 2016 and he couldn't play the game he loved due to chronic heart and kidney failure.

Glen was born with congenital heart disease – he was a blue baby. Glen was two weeks old when he had his first operation to repair a hole in his heart, which normally closes very soon after birth without assistance in most children.

Glen was also born with his heart on the wrong side and back-to-front.

These issues were fixed in the next few years with operations including a switch operation and a *mustard repair* operation. At the age of 18 Glen had a mechanical artificial aortic valve replacement done.

At 42, Glen's heart function started declining, and a defibrillator was implanted at the Royal Melbourne Hospital.

Glen Jones

With Glen's health rapidly declining he underwent many tests and scans, as well as vein mapping etc to finally be put onto the active heart and kidney transplant waiting list. Glen also needed a kidney transplant due to a lifetime of medication to assist the heart.

Glen was listed for a heart and kidney transplant in June 2018 and in August of that year, Glen was given the greatest gift of all, receiving a heart and kidney transplant at the Alfred Hospital.

One of the goals that Glen worked on with Lou Fuller in the gym was to be able to get back to playing lawn bowls, his great passion.

Two years later Glen was back playing lawn bowls and is lead in the Division 2 Pennant team at our local bowling club.

Glen is grateful every day for the gift that he has been given. As everyone who has been down the transplant path knows, it takes a huge toll on every member of the family not just the recipient.

Whilst sitting in ICU waiting for my husband to wake up from his heart and kidney transplant I started crocheting squares to make a 'journey blanket' as a reminder of the long journey that Glen and I had been on from transplantation to returning home to our boys, which was three and a half months in total.

Many times I have been asked by staff, patients and visitors at the hospital what I was crocheting, and my reply was a 'journey blanket'.

We are so grateful for the care and support that we have received from all the staff at The Alfred (some have turned into lifelong friends) that I wanted to do something to give back.

Having been through the journey of being a carer to a family member that received a heart and kidney transplant, I am aware that being away from family and friends (especially travelling from interstate like we did) can take a big toll emotionally not only on the transplant recipient but also on their carer who is normally a partner or parent.

After some thought and an email to the hospital asking their permission, I came to the decision that I would do transplant knee rugs in the *DonateLife* colours for transplant recipients at The Alfred. It is my way of letting the families know that someone is thinking of them.

In the two years we have been home since my husband's transplants, I have donated approximately 100 knee rugs. It truly is a labour of love!

Trudi Jones

TRANSPLANT 2020 ANNIVERSARIES

HEART

NOVEMBER

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

DECEMBER

John Jones 1989
Don Browne-Kerr 1997
David Hales 1998
John Bisiach 2002
Gaylynn Pinniger 2002
Greg Dartnell 2004
David Ash 2008
Helen Rankin 2011
Rodney Withford 2011
Jane Buxton 2014
Peter Grimsted 2016
Stepen Patching 2017
Paul Grassick 2019

JANUARY

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

HEART + LUNGS

NOVEMBER

Daniel Harwood 2018

LUNGS

NOVEMBER

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

DECEMBER

Alison Walters 2004
Wendy Jenkins 2006
Kevin Avery 2015
Tony Hyams 2015
Ilene Henderson 2015
Vic Reynolds 2018
Jessica Luxford 2019

JANUARY

Marilyn Stephens 2003
George Bouios 2008
Elizabeth Johnson 2013
Ann-Marie Dunbar 2014
Christopher Teese 2014
Patricia Newell 2017
Brooke Evans 2018
Josie Barrett 2019
David Thurbon 2019

Committee meetings 2021

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

Meeting 1/4 - Tues 9 Feb, 2021
Meeting 2/4 - Tues 11 May, 2021
Meeting 3/4 - Tues 10 Aug, 2021
Meeting 4/4 - Tues 9 Nov, 2021
** AGM followed by normal committee meeting*

Meetings are usually held at the Alfred, Fifth Floor, Ward 5 East, Seminar Room at 7.30pm with the Committee meeting in Alf's Café at 7pm for a catch up.

But until the COVID-19 pandemic has been completely mitigated within Victoria, all committee meetings will be conducted by *Zoom*. All members are welcome to Zoom into the meetings!

Member Events 2021

- **Easter BBQ** – Sun 28 Mar
- **Xmas BBQ** – Sun 28 Nov
- **DonateLife Week**
  26 July - 1 Aug
- **DonateLife Thank You Day**
  21 Nov
- **Service of Remembrance**
  Last Saturday in May (Victoria

Please note all venues and dates will be confirmed later

Circulator content deadlines

- **First quarter** – Fri 19 Mar
- **Second quarter** – Fri 21 May
- **Third quarter** – Fri 17 Sept
- **Fourth quarter** – Fri 26 Nov

We'd love to hear about your experiences pre and post transplant. Send your contributions to circulator@hlttv.org.au

What is your BMI?

Are you within a health weight range for your height?

Body mass index, or BMI, is used to determine whether you are in a healthy weight range for your height. It is useful to consider BMI alongside waist circumference, as waist measurement helps to assess risk by measuring the amount of fat carried around your middle. Find out about BMI and use the online calculator to test yours at:

www.heartfoundation.org.au/bmi-calculator

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

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

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

HLTTV Signature Program

HLTTV Second Chance Accommodation Program

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

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

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

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

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

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

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

The HLTTV provides a wide range of support

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

Our services and programs include:

Second Chance Accommodation Program (SCAP)

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

Donations to The Alfred

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

Fitness Grants

The HLTTV will reimburse eligible post-transplant members 50% of receipted costs up to a $150 maximum* to cover the cost of appropriate fitness activities and equipment (eg mats, 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 The Alfred Hospital and a Gala Dinner which acts as a major fundraiser for the Trust. We can also assist members with regional events.

Visit us at www.hlttv.org.au

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

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 ☐

***CIRCULATOR* NEWSLETTER**
I wish my copy to be emailed ☐ I wish my copy to be posted ☐

MEMBERSHIP TYPE
RECIPIENT
(Please complete information regarding Transplant Type, Operation, Month and Year – this allows us to celebrate transplant anniversaries if you consent below).

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

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

OR ***PRE-TRANSPLANT*** (Waiting list)
OR ***CARER*** | ***SUPPORTER*** | ***OTHER*** (please specify)

Signature Date

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

A membership reminder will be included with the Winter edition of *'the Circulator'* each year. Prompt payment on receipt of a membership invoice is appreciated and we are grateful for any additional donations. Donations over $2 are tax deductible.

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**

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.

In **2019** there were

113

Heart transplants

183

Lung transplants

Register as an organ and tissue donor today at **donatelife.gov.au**

donatelife