The Circulator

Heart & Lung Transplant Trust of Victoria Magazine | Edition 104 | Spring 2023

All the stars aligned for Mary Dermis

VALE Maarit Moilanen

A much loved HLTTV Committee member, having time to see her children grow and flourish was the greatest gift her heart transplant bestowed. Page **6**

The first few days

Transplant Australia is a great source of information about those first tentative days when you are trying to work out life after transplant. Page **24**

Top tips for travel

If your goal post transplant is to travel, you need to consider a variety of issues to ensure a safe, enjoyable trip. Page **43**

HLTTV
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.

We support and promote

Highlights

Edition 104 Spring 2023

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

Cover image: Heart transplant recipient Mary Dermis with The Alfred's Senior Physiotherapist and Churchill Fellowship winner Louise Fuller (left) and Mary's transplant surgeon, The Alfred's Director, Cardiothoracic Surgery, Silvana Marasco (right)

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President's message

Welcome to the Spring edition and thank you to our HLTTV community for their ongoing support

Hello everyone, my name is Tessa Keegel and I'm the President of the HLTTV. Many thanks to our wonderful editor Graeme Klemm who has worked so hard on preparing this magnificent 2023 edition of The Circulator.

What a year we've had! First, I want to thank our immediate past President Belinda MacLeod-Smith. Belinda's vision and passion has guided us through the past years. She has contributed on so many levels, particularly through the challenges we've faced because of the COVID-19 pandemic.

Belinda's professional experience as a leader in consumer health advocacy has helped us to grow as an organisation. In true Belinda style, she isn't stepping back completely, but has continued as a member of the committee taking up the role of Acting Secretary for the HLTTV. We thank you for everything you've done Belinda.

We have also had to say goodbye to some of our dear friends, especially for all of us our dear Maarit Moilanen. Maarit was the secretary for HLTTV for many years. We could always depend on her, as well as her husband James, and other members of her family, to do whatever was needed. We miss her so much. We will think of ways that the HLTTV can honour Maarit and keep her in our memories.

One of our main activities at HLTTV is organising the Second Chance Accommodation Program (SCAP). This program helps to fund accommodation for people who are in the process of receiving transplants and who live more than 100 kms from The Alfred.

Since 2012, SCAP has been successfully supported by the HLTTV. Funding activities have included the 2014 and 2016 Tour de Transplant, a bicycle tour organised by the HLTTV and led by Australian professional cyclist Phil Anderson. In 2023 we've made a big change to SCAP with our move to a new provider, Rockmans Apartments. Transplant recipients and their families seem to be very happy with the move.

In the past few years our SCAP fund-raising activities have been severely curtailed because of the Covid-19 pandemic. However, at the end of 2022 we were successful in gaining **$40,000** from the **Collier Trust** through the **Lord Mayor's Charitable Foundation.**

Another important contribution towards SCAP is from the generosity of our donors. These include donors such as the **Camperdown Nursery and Mart,** who under the leadership of **Bec Rohan** (pictured below with Yarra Valley Auctions' Gary Latham), held a fundraising event in February 2023 and raised **$12,216.**

We also recognise the support we received from the tattoo artists from **Brunswick Fruit Shop**, who raised **$2,000.**

We also want to thank donors such as the **Rotary Club in Torquay** who regularly contribute to the HLTTV, as well as all the other donors who have been so generous in supporting us over the years.

We've done many things since our last edition of The Circulator. Early on in 2022, our committee members, Petra, Sam and Martina went sky-diving for DonateLife.

Later in that year Sam and Martina were busy signing up cafes for DonateLife week.

Amongst other fundraising activities, Petra organised a morning tea for her workplace. Sam also had great success at the 2023 World Transplant Games in Perth bringing home a silver medal in ten pin bowling and a bronze medal in darts. Congratulations Sam!

We've also kept up with the education sessions for people who've recently received heart or lung transplants from The Alfred.

Martina has continued her work organising the Heart-to-Heart respite house in Barmah on the Murray River.

Shinade Appelman with 'Easter Bunny' James Ure

We have also had successful HLTTV BBQs, one in November 2022 and the other in March 2023. We have another BBQ planned for the end of the year, as well as a cinema event in October (more information will be available soon).

Finally, I want to thank all the magnificent members of the HLTTV for everything that we've worked on over the past year. Thanks especially to our Acting Secretary Belinda MacLeod-Smith, Martina McArdle for everything she does, our treasurer Sue Laksassi, our new Membership Officer Wanda Moyle, Sam Ira, Petra Brosch, Claude Turco, Louisa Walsh, Gaylynn Pinniger and the editor of The Circulator and other HLTTV publications, Graeme Klemm.

We need some new HLTTV committee members, please consider nominating. We hold four meetings a year and plan fund raising activities and conduct other HLTTV business. The meetings are held over the internet so committee members can be located anywhere in Australia. It would be great to have some other committee members who have first-hand experience of using SCAP.

Please get in contact with me at president@hlttv.org.au if you are interested in getting involved.

Looking forward to celebrating with everyone at the end of year HLTTV BBQ on Sunday the 26th of November. Here's to a successful 2023!

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VALE

Wife, mother, friend and advocate

Time to see her children grow and flourish was the greatest gift her heart transplant bestowed.

On 1 November last year we said goodbye to our beautiful wife and mother Maarit. She left us peacefully after a difficult battle with Covid and consequent complications.

Maarit had been in the Intensive Care Unit (ICU) at the Alfred Hospital for the last three weeks of her life. We would like you to know her passing was calm and pain-free, and she was with her family in the ICU – James, Elena, Nick, and Zac – in her final hours and at the end.

She has left a huge hole in our hearts and in our lives, and our grief has been overwhelming at times, and it is still raw now, eight months later. We are not the first family to lose a loved one, and many others have had to suffer through the pain and anguish of the loss of a wife, mother, daughter, sister and friend. We know this, but it doesn't make things any easier.

But life goes on, and as Maarit desperately wanted us to, we are facing up to life without her vibrant and life-affirming presence to support us.

We have no doubt though she is still with us, and her spirit will still guide us and support us.

We have each other and we have the love and support of our families and our friends. Their place in our lives over the last eight months has been invaluable, and we are so grateful.

Maarit had a heart transplant at the Alfred Hospital in June 2010. This enabled us to have twelve years of life with Maarit that almost certainly would not have occurred otherwise.

Her transplant was a blessing for which we are so grateful. It was hugely significant in her life on a whole range of fronts – she could do lots of things that had become impossible in the last few years pre-transplant – it was joyful.

We always remember that this was only possible because of the extraordinary gift from an organ donor and the donor's family.

And, of course, the skill and dedication of the surgeons, doctors, nurses and support staff at the Alfred Hospital – the 'miracle-workers' as we called them.

Maarit was always acutely aware of this gift she had received, and spent every day living life 'to-the-full' in honour of her donor and his/her family. As she said often, her new heart gave her the precious opportunity to see her three children grow up and become wonderful, caring and responsible adults. This was one of the most important things in Maarit's life.

Following her transplant, Maarit also became very aware of her new extended 'family' – the transplant community. She developed strong and lasting friendships with other transplant recipients at the Alfred Hospital, and their carers and families. And she became a passionate supporter of HLTTV, and its invaluable work in supporting the transplant community.

Helping with HLTTV and its work was one of the most important developments in Maarit's life post-transplant. And her participation in HLTTV gave her great joy and satisfaction. We know that Maarit would want us to take this opportunity to encourage everyone touched by a transplant to support HLTTV – either by joining its committee, or helping with all of the activities and initiatives it undertakes.

Since Maarit left us we have received lots of wonderful tributes, cards, phone calls and messages – all of which we have found really moving, and which have all reflected on what a truly wonderful and inspiring wife, mother, daughter, sister, aunty and friend Maarit was – thank you to everyone so much for this kindness, and all of the support we have received. We are really grateful for all of these things.

James Ure, Elena, Nick and Zac Ure-Moilanen

The family celebrating the 10th anniversary of Maarit's heart transplant

All the stars aligned

Exceptional women worked together to forge Mary's success

By Graeme Klemm and Mary Dermis | *Heart transplant 1 March, 2021*

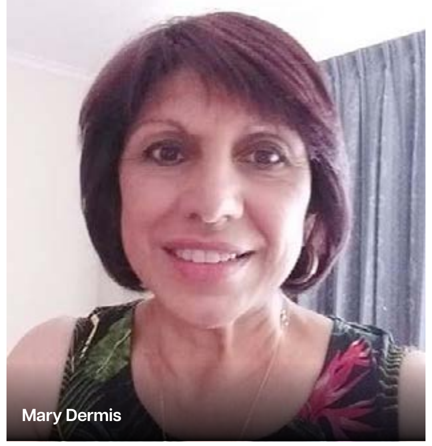
Mary Dermis, currently 62 years of age, had a heart transplant recently at The Alfred and her story celebrates the work of three exceptional women – her cardiologist, her surgeon and her physiotherapist – in getting her to, through and beyond the most significant moment in her life.

Mary recalled having a heart murmur when she was a teenager and first consulted a cardiologist, Dr Heddle at the Ashford Specialist Centre.

Mary was diagnosed with a condition called **Hypertrophic obstructive cardiomyopathy** *(see explanation and graphics on facing page)* in 1997 and was prescribed medication to manage her condition.

While controlling some of her symptoms, as time passed she began to deteriorate and was eventually given advice that she may require a heart transplant.

Mary underwent a number of ablations – a procedure to treat atrial fibrillation and uses small burns or freezes to cause some scarring on the inside of the heart to help break up the electrical signals that cause irregular heartbeats. This can help the heart maintain a normal heart rhythm.



Mary Dermis

This stabilised Mary's condition for some time.

She initially had a pacemaker inserted in 2000 but needed to upgrade it to an ICD (which includes a defibrillator) just eight months later. Unfortunately there was a fault in the battery which required the ICD to be replaced a year later. To add further frustration to Mary's situation the lead became detached and she needed to undergo another operation to replace the lead.

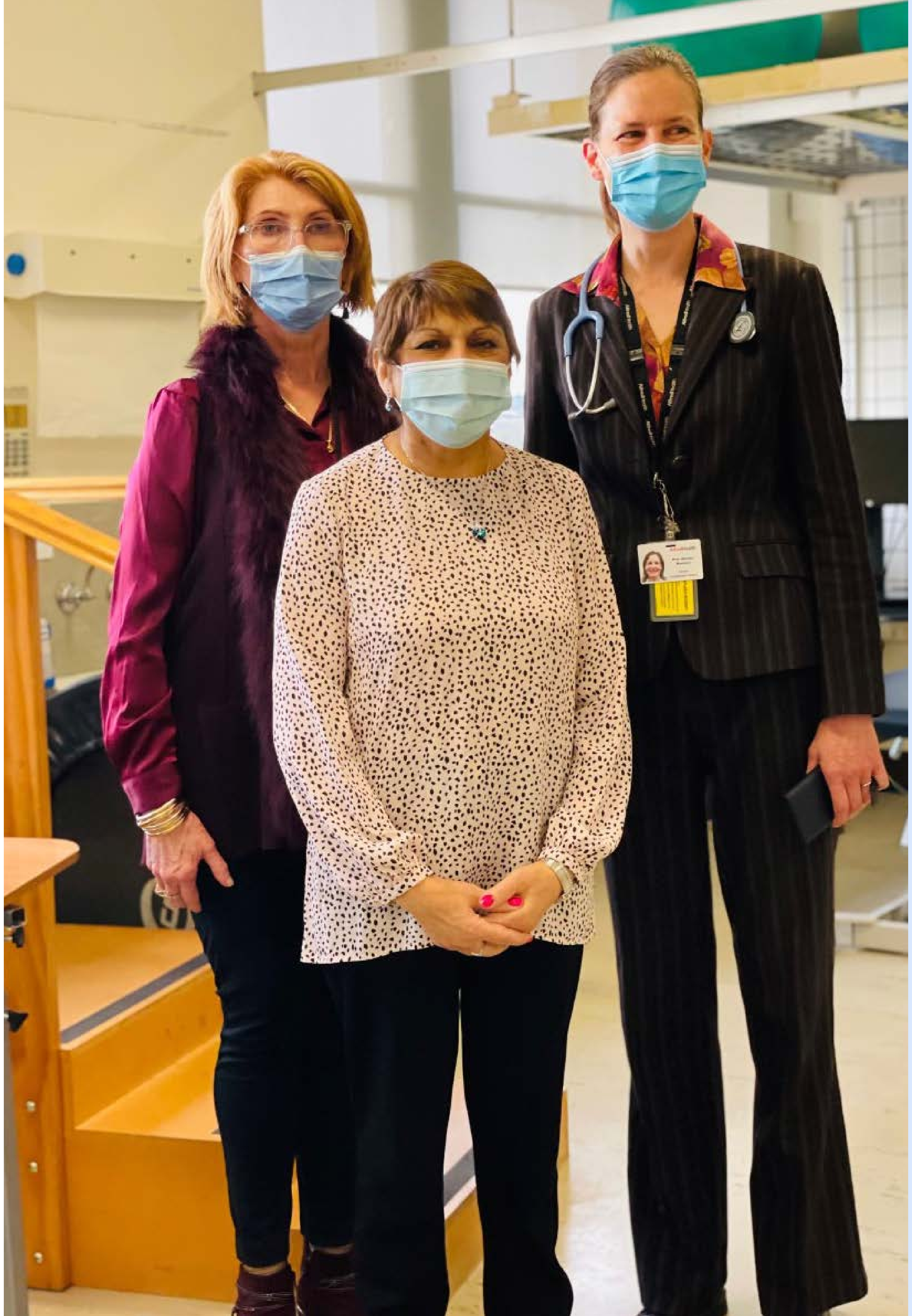
Although this meant Mary started to feel a little better physically, there were continued issues with both the leads and the battery which caused unexpected, and certainly unwanted, shocks – sometimes up to 12-15 at a time. As you can imagine, this was causing a great deal of stress and anxiety for her and her family.

By 2018, and in her late 50's, Mary was trying as hard as she could to maintain her normal routines within the family, cleaning, cooking and especially baking which was a passion of hers.

However, as hard as she tried, her condition meant that she was deteriorating and slowing down, with everything becoming a struggle.

She found herself out of breath, constantly tired, had a poor appetite and was vomiting and experiencing bouts of diarrhea which caused her to lose weight.

Article continues on page 10...



What is Hypertrophic cardiomyopathy?

Hypertrophic cardiomyopathy (HCM) is an inherited condition that results in an abnormally thickened heart muscle. It is the most common inherited heart muscle condition affecting up to 1 in 200 of the general population.

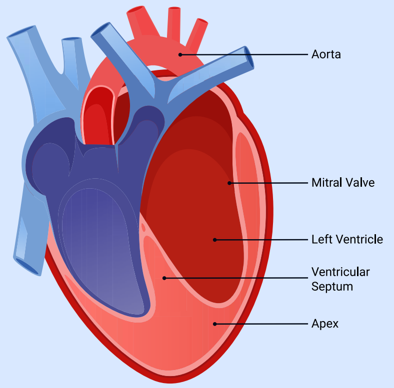
The genetic mutation (or 'spelling mistake' in the genes) leads to inefficient heart muscle contraction as it affects the genes that code for the heart muscle proteins usually critical to cardiac contraction.

The inefficient heart muscle contraction over time is thought to lead to heart muscle thickening which then leads to symptoms such as chest pain, shortness of breath, dizziness, fainting episodes or irregular heartbeats (arrhythmias).

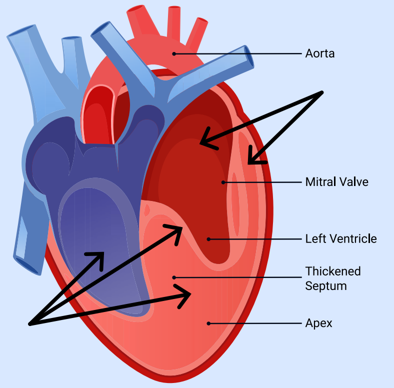
Occasionally, the disease may cause sudden death from cardiac arrest.

The thickness of the heart muscle is one of the most important predictors of symptoms in patients with HCM.

Normal heart



Hypertrophic heart



Courtesy: www.heartfoundation.org.au

Mary underwent a fairly straightforward heart operation from the surgical point of view. The donor heart was very good quality and an excellent size match for Mary. She was very lucky to have a heart that had been preserved using a new technique, rather than just having it preserved in an esky on ice which has been the standard technique for decades.

Prof. Silvana Marasco
Director Cardiothoracic Surgery & Transplantation
Alfred Hospital

Mary completed her rehabilitation following her heart transplant. She worked extremely hard in the gym and is looking forward to some social tennis, playing with her grandchildren and joining a local walking group to maintain her new found fitness.

Louise Fuller
Senior Physiotherapist
Alfred Hospital

In early 2019 Mary was referred to **Assoc Prof Christine Burdeniuk** (pictured below) who treats advanced heart failure patients throughout the Southern Adelaide Local Health Network and is heavily involved in the selection and care of heart transplant recipients in South Australia.

Assoc Prof Christine Burdeniuk

The discussion about a possible heart transplant wasn't something that Mary had anticipated or was ready for – "I didn't think I was that bad as I had been living with this for so long, I had lost perspective as to what was normal", recalled Mary.

Mary had one last attempt at stabilising her heart condition using an ablation, but within six months it was clear that a transplant was the only viable option available to her.

By the end of October 2020 Mary, now under the care of Assoc Prof Christine Burdeniuk, committed to pursuing the path to a heart transplant. She underwent a range of tests and checkups at the Flinders Medical Centre and then at the Alfred Hospital in Melbourne.

The 'Heart in a box' or XVIVO perfusion system which Mary Dermis agreed to participate in was the culmination of research done at The Alfred by Prof David McGiffin and Prof David Kaye.

Originally developed in Sweden, the Alfred team have proven that hypothermic machine perfusion can safely keep donated hearts alive outside the body for up to nine hours – more than double the current standard time using ice slush.

See page 58-59 for the full article

After successfully completing the work-up, Mary was listed by The Alfred transplant team but not activated immediately as she required some further management and tests in Adelaide.

Mary also agreed to be part of a new trial being conducted by The Alfred which utilised 'Heart in a box' technology initially developed in Sweden.

It was Christmas eve 2020 when Mary received notification that she had been activated on the transplant list so she did what many listed patients do – pack her bags ready for 'the call'.

"It was 11pm on Sunday 28 February that I received the phone call from The Alfred that a heart had become available for me. I was in complete shock. Nervous and excited at the same time."

"I threw some extra things in my bag and told my husband, Peter, that unfortunately he couldn't come on my flight with the Royal Flying Doctor Service as they only had room for me (getting the heart) and another patient who was going to receive the lungs from the same donor."

Once Mary landed in Melbourne she was taken to The Alfred, admitted through Emergency and underwent some tests and an x-ray before going into the pre-op area for sedation prior to her transplant.

Mary spend a period of three weeks in ICU after transplant as her body acclimatised to the new heart. She experienced some challenges during the period in ICU. Her legs were swollen with fluid retention due to her kidneys not adjusting to the heavy dose of anti-rejection medication. The nasal gastric feeding tube was still being used but Mary tried very hard to eat as much as she could so she could have it removed as it was very uncomfortable.

The Prednisolone medication post transplant is usually a very high dose and Mary found herself experiencing the shakes like most patients. She gradually found it easier to lift her arms, sit up and eventually sit on the side of the bed and find her feet.

"It was the best feeling being able to get out of bed and go to the toilet and eventually have a shower for the first time in three weeks", she said.

Mary progressed to the ward and started moving around with a walker to increase her strength as the days passed.

"I couldn't believe when I got to the gym. Even though I didn't think it was much, I was actually doing more exercise than I had in years. It was incredible how quickly I was progressing."

The whole experience seemed pretty surreal to Mary and she found herself spending a lot of time just sitting in her room thinking. This contemplative time sparked a desire to put some of her thoughts on paper and motivated her to try her hand at poetry, albeit pretty wobbly from the 'Pred shakes' at the start.

"I could scribble thoughts on paper, even funny words to do with little things that mattered at that time. I thanked the staff in a poem about the gym which I had laminated and put up on the wall when I presented it on my last day there", Mary recalled.

"My first poem was about my transplant when I was told it was special because I was the first person in the Southern Hemisphere to receive a heart in a box."

Mary spent over five months in Melbourne, using that time to undergo the mandatory post transplant rehabilitation program that empowers recipients to understand all of the issues that will help them navigate their new normal – medications, diet, exercise, infection control, possible return to work and more.

The Heart & Lung Transplant Trust of Victoria, through their 'Second Chance Accommodation Program' was able to assist Mary with her accommodation during the five months she spent in Melbourne. The HLTTV provide heavily subsidised accommodation for transplant recipients and their partners or carers during the rehabilitation, particularly those that come from interstate or Victorians who live over 100km from Melbourne. By easing this sometimes significant financial burden, the HLTTV play their part in assisting the heart and lung transplant community.

"To my donor and family, I'm so sorry that there had to be a loss of life for me to have the opportunity to live mine. I am so grateful and thankful for the opportunity to keep living my life and now seeing it with different eyes, I appreciate even the smallest of things. I promise to look after my new heart the best I can and not take it for granted. From the bottom of my 'new' heart, I thank you so very much", said Mary.

With all the hard, but necessary work since her transplant, Mary's is an amazing story, made even more memorable by the fact that, in the end, it was all four women that worked together to ensure that she had the very best outcome and a second chance to live longer and enjoy her life.

The Gift

The pump to our soul is our heart
treat it with respect from the start.
You will be rewarded if you do
by living, breathing, enjoying life as
you want to.

If bad luck comes your way
you can't control or have a say.
When your heart decides to fail
through circumstances unprevailed
there is hope and a new road to life,
with science moving fast
your prayer will be answered at last.

A heart in a box can come your way,
beating as well as can be.
A new lease on life you will see,
I am living proof of this.
My wish was finally granted,
a new life I have now started.

A poem by Mary Dermis

Mary, post transplant, with husband Peter getting back to enjoying their life with family and friends

ROCKMANS APARTMENTS

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Adorned with deluxe fixtures and fittings, the Rockmans Serviced Apartments are designed for the comfort and sophistication; the perfect long or short term escape, and especially for patients, and carer, as they transition from the Alfred Hospital to independant living during their rehabilitation after transplant.

Titled the 'Most livable city in the world' Melbourne is flourishing, from global sporting events, superstar music concerts, highly acclaimed theatre shows and celebrated art exhibitions, it's all happening here.

The wonderful shopping districts of Chapel Street, the vibrant nightlife of Richmond, the eclectic vibe of St Kilda beach, the idyllic natural beauty of the Yarra River and the health precinct including the Alfred Hospital and Baker Institute all within walking distance through beautiful Fawkner Park.

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

Your host
Robert Rockman

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Comfort and security
- Air conditioner
- Bed sheets and towels
- Hair dryer
- Alarm clock radio
- Steam iron & ironing board
- Washing machine & dryer
- Secure swipe entry to building
- Secure entrance

Kitchen
- Fridge
- Built in electric oven
- Microwave oven
- Cooker hob & hood
- Dishwasher
- Electric kettle
- Toaster
- Glassware, crockery, cutlery & utensils

www.rockmansapartments.com.au

There's an App for that!

Why not let technology do some of the work?

By Lyall Pearce | *Heart transplant 1 July, 2020*

As a recent heart transplant recipient and long time AL Amyloidosis sufferer, I found I was being requested to keep track of things like weight, blood pressure, blood glucose and my fluid intake.

All of these records became somewhat tedious so I researched ways to simplify the entire task.

Initially, I started with the paperwork I was given. With my hand writing approaching the readability of a doctor's writing, using paper and pen proved cumbersome and difficult.

There had to be a better way. Subsequent research found that my phone, either an iPhone or Android, could do all the tasks I needed to keep the doctors and nurses happy and to simplify my own life.

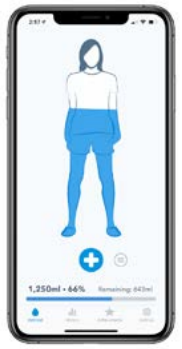
Let's start with before the heart transplant, when I was having lots of difficulty with my body no longer working as desired, due to my failing heart. I suffered low blood pressure, to the point of fainting and fluid retention. I was instructed to monitor my blood pressure and my fluid intake. My weight was also to be monitored, as it rose and fell, depending upon how much fluid I was retaining.

Blood pressure was relatively easy, though, not without cost. At my local chemist, a blood pressure band built by **iHealth** not only recorded my blood pressure but also my heart rate.

No mucking around with a display and writing the details down, it connected directly to my phone using bluetooth and an App which I downloaded from the App store. Now, I simply put the band on, it realises that it's being used and talks to my phone. The app shows a 'start' button, which I press, and away it goes. Job done in 30 seconds. No stethoscopes or anything else. I can look at previous readings, when they where taken, see trends, etc.

If you have an iPhone, you also have an app called **Health**. I granted my Blood pressure App access to 'Health', so it automatically records my blood pressure and heart rate in the Apple Health App.

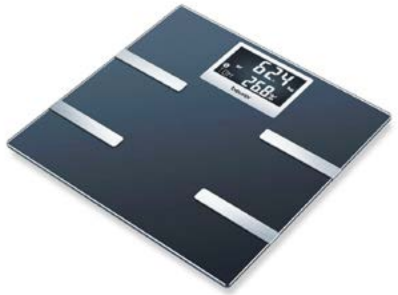
On to my Fluid monitoring – a bit of a search through the App store and I found **WaterMinder**, there is a myriad of other apps that appear to do the same thing, but this is the one I used.



I setup 4 'quick drinks' such as 200ml of Coffee, 100ml of Milk, 50ml of Espresso, 300ml for my Breakfast Cereal.

Now, when I have a drink, I open the app, click one of the 4 quick drinks and I am done. If I am drinking something unusual, I can manually enter the type and quantity. The App provides a target such that I can say, "I want to drink no more than 1.5 litres per day", and it shows a body outline that gradually fills with water, so I can see how I am progressing for the day. The fluid monitoring app also can load data into the Apple Health app.

My weight is taken care of by my bathroom scales, which is a Beurer model.



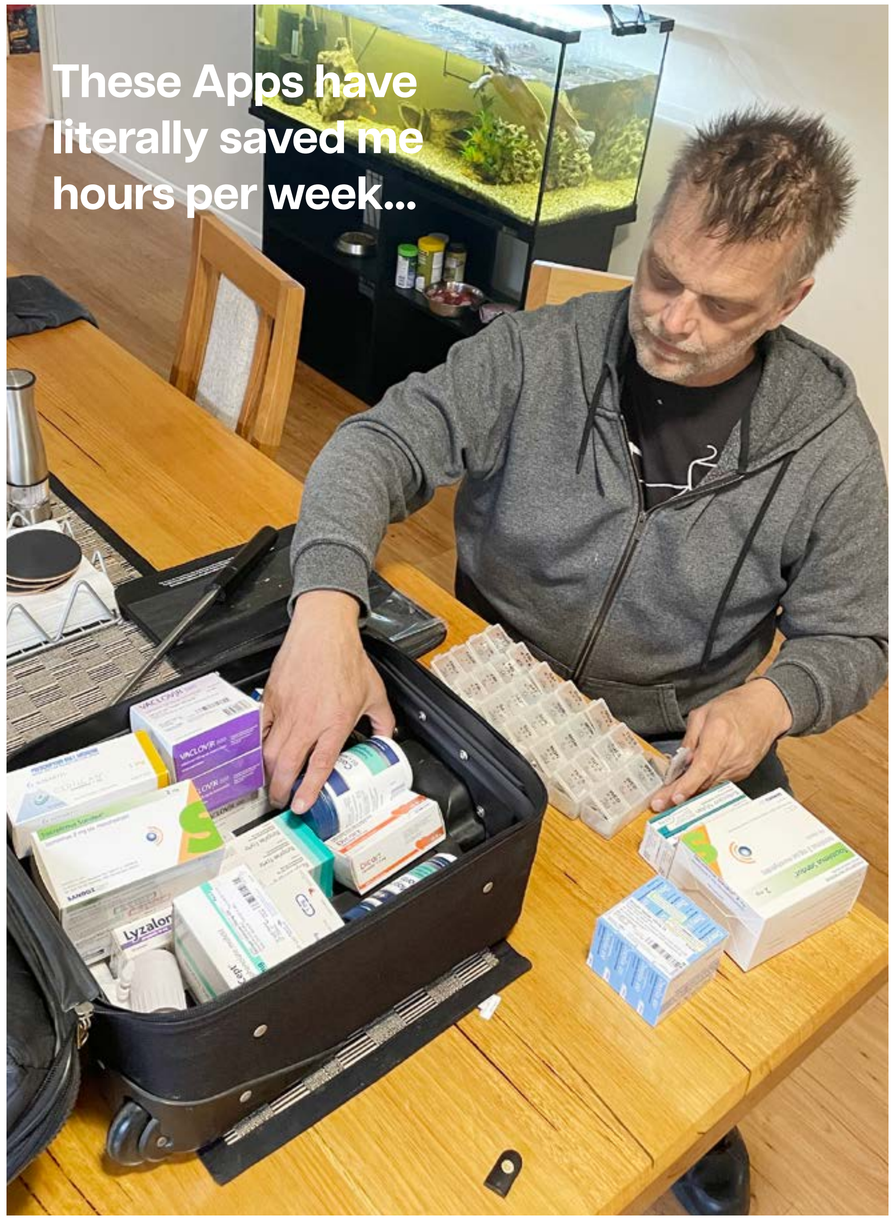
Again, it connects to an App to keep track of my weight.

73.6 kg

Date 29/08/2018
Time 12:21 PM
Change -0.7 kg

BMI 23.2
20.7%

The scale is set up to recognise a few people and keeps records of their weight, if the phone is not nearby.



These Apps have literally saved me hours per week...

Once the phone is nearby, and the Bathroom Scale app is running, it connects and uploads all the weight measurements. Once more, this can be loaded into the Apple Health App.

After my heart transplant, I received one of those 7 day 5 slot pill dispensing folders from Transplant Australia.

In addition to the monitoring, above, I now had to take a myriad of pills, many of which, initially, I could not even pronounce, let alone remember. Of course, things are different now, I can rattle off the names, dosages, etc.

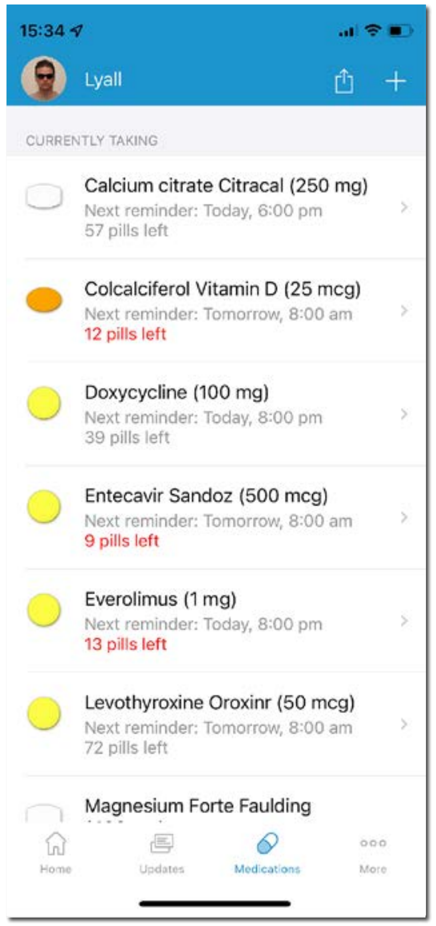
In addition to this pill folder, I was given a 'Blue Book', in which the hospital pharmacy wrote what medications I was to take, when and how much.

Of course, the first thing that happened was this booklet fell apart. I moved to a laptop spreadsheet, duplicating the Blue Book as a spreadsheet. This lasted for a while, and I still use this spreadsheet during my weekly pill dispenses (I fill my pill boxes once a week).

However, a laptop is a little bulky and awkward, so a little research in the App store and I found a free App called **Medisafe**.

In this application, you have to initially load up your medications, when to take them and how much. It's not as hard as you think, you don't have to name the medications correctly, you can simply call it Tac, or Myco, not the full medical name (Tacrolimus or Mycophenolate). So long as you understand what it means, that is all that matters.

You can setup what the medication looks like, is it a yellow circular pill or is it a white capsule. Again, it's up to you. You can also setup how many tablets/capsules you have in stock and at what point the App should remind you that you are running low, so you can re-order more.



Calcium citrate Citracal (250 mg)
Next reminder: Today, 6:00 pm
57 pills left

Colcalciferol Vitamin D (25 mcg)
Next reminder: Tomorrow, 8:00 am
12 pills left

Doxycycline (100 mg)
Next reminder: Today, 8:00 pm
39 pills left

Entecavir Sandoz (500 mcg)
Next reminder: Tomorrow, 8:00 am
9 pills left

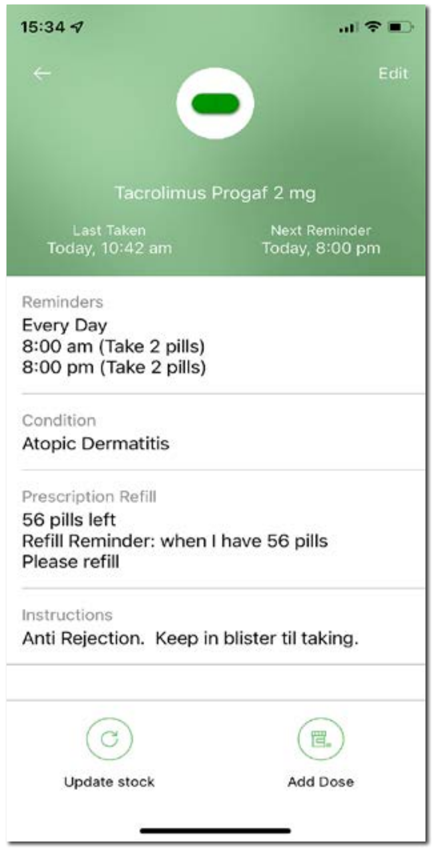
Everolimus (1 mg)
Next reminder: Today, 8:00 pm
13 pills left

Levothyroxine Oroxinr (50 mcg)
Next reminder: Tomorrow, 8:00 am
72 pills left

Magnesium Forte Faulding

I dutifully set up all the drugs with meaningful names, setup schedules such as 8am take 4mg Tac, 8pm take 4mg of Tac. I have 100 capsules of Tac in hand, remind me when I have 56 capsules left (2 weeks supply) so that I can order more.

Now, at 8am, and at 8pm, the app makes a sound (I like the default, it sounds like a pill bottle rattling for about 3 seconds) to remind me to take my Tac, and any other tablets that I have on the same schedule.



Tacrolimus Prograf 2 mg

Last Taken
Today, 10:42 am

Next Reminder
Today, 8:00 pm

Reminders
Every Day
8:00 am (Take 2 pills)
8:00 pm (Take 2 pills)

Condition
Atopic Dermatitis

Prescription Refill
56 pills left
Refill Reminder: when I have 56 pills
Please refill

Instructions
Anti Rejection. Keep in blister til taking.

If I am late, that's OK, I can record the time I actually took the tablets. If I don't have my phone on me at the time, I can update the phone, at a later time. Or, I can 'skip' a dose entirely (I forgot that calcium capsule again).

An additional benefit to the App is, I can show a medical person my dosage and schedule and even share, by email, my dosage schedule.

No more of this 'I take X tablets of Y at Z time', oh, I forgot, I also take...

A nice feature in **MediSafe** is to nominate 0.5 (half) a tablet – it's not obvious you can set this – simply enter 0.5 instead of 1.0 when it comes to entering the number of pills.

Finally, MediSafe has the concept of **'MediFriends'**. MediFriends are people who will be notified if you are late taking your tablets. This can be your partner or carer, it's up to you. If, for some reason, you do not record in MediSafe, that you have taken your medications, your MediFriend is notified so that they can nag you.

Alternatively, if you are terribly ill, they could call the ambulance, although, I prefer to think in the first case, rather than the second.

This is all well and good, but now I not only have a huge pile of pill boxes, whose contents are now managed by the MediSafe App, I have a pile of prescriptions to keep track of. Have I got enough repeats left? Do I need a new prescription because the old one has run out of repeats? Have the prescriptions expired?

To solve this problem, I found an App called **MedAdvisor**.

I register an account, choose a pharmacy that supports using MedAdvisor (I use National Pharmacies), go to my pharmacy of choice, prescriptions in hand and say "Please load ALL these prescriptions in to MedAdvisor, do not dispense them."

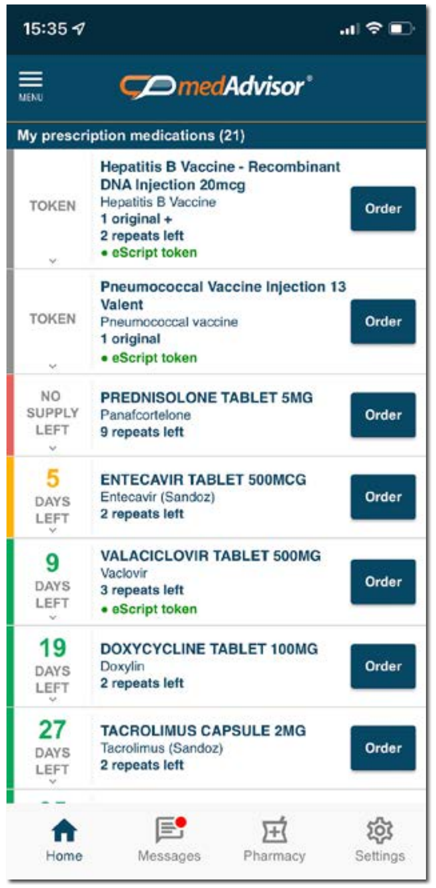
From that point on, all the prescriptions show up in the MedAdvisor App (above right), along with the drug name, the prescribed dosage and how many repeats I have left.

The added advantage, I no longer have any paperwork!

When MediSafe tells me it's time to reorder (MedAdvisor can do this too, more on that in a minute), I simply go to MedAdvisor and click the 'Order' button next to the required prescription(s) and my pharmacy (in my case National Pharmacies) will be notified that I want these prescriptions filled (right)

I am subsequently notified when the prescription is available for pickup or they can be delivered to me.

If I pick them up, I can simply walk in the pharmacy, pick up my order, pay and go, no more waiting around for the pharmacist to fill the prescription, no more paperwork getting lost under the couch. It's all in the App. Since I can see how many repeats are left on a prescription, I know when to schedule an appointment to obtain a new prescription.



My prescription medications (21)

TOKEN
Hepatitis B Vaccine - Recombinant DNA Injection 20mcg
Hepatitis B Vaccine
1 original +
2 repeats left
• eScript token

TOKEN
Pneumococcal Vaccine Injection 13 Valent
Pneumococcal vaccine
1 original
• eScript token

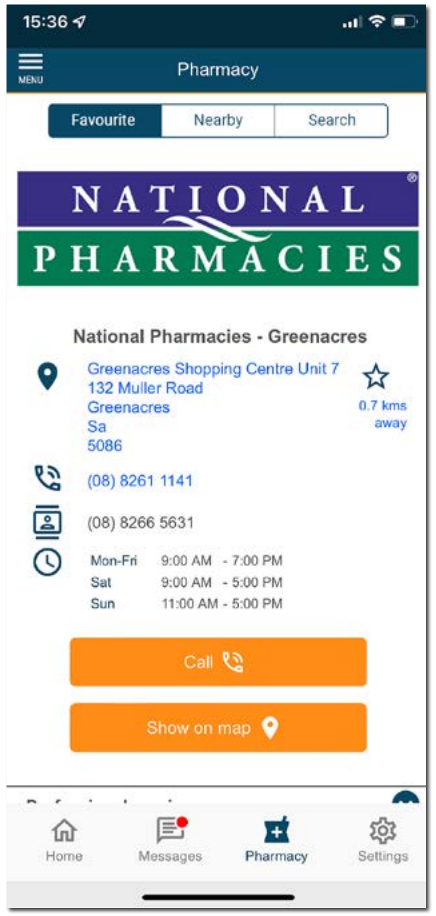
NO SUPPLY LEFT
PREDNISOLONE TABLET 5MG
Panafcortelone
9 repeats left

5 DAYS LEFT
ENTECAVIR TABLET 500MCG
Entecavir (Sandoz)
2 repeats left

9 DAYS LEFT
VALACICLOVIR TABLET 500MG
Vaclovir
3 repeats left
• eScript token

19 DAYS LEFT
DOXYCYCLINE TABLET 100MG
Doxylin
2 repeats left

27 DAYS LEFT
TACROLIMUS CAPSULE 2MG
Tacrolimus (Sandoz)
2 repeats left



National Pharmacies - Greenacres

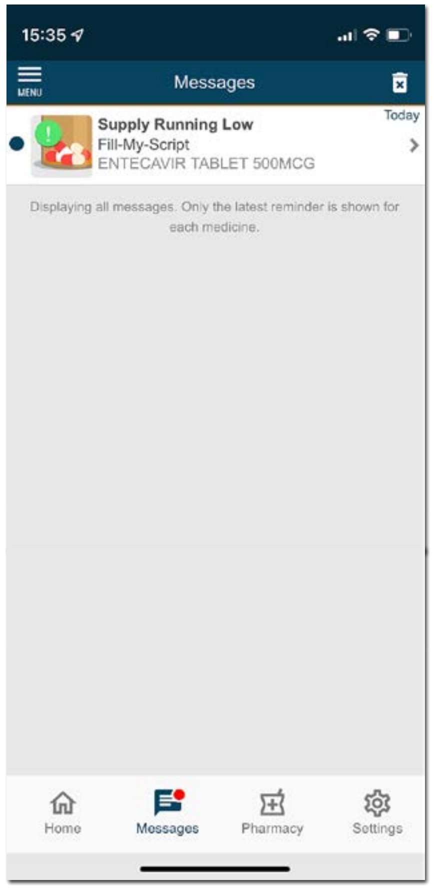
Greenacres Shopping Centre Unit 7
132 Muller Road
Greenacres
Sa
5086

0.7 kms away

(08) 8261 1141

(08) 8266 5631

Mon-Fri 9:00 AM - 7:00 PM
Sat 9:00 AM - 5:00 PM
Sun 11:00 AM - 5:00 PM



Supply Running Low
Fill-My-Script
ENTECAVIR TABLET 500MCG

Displaying all messages. Only the latest reminder is shown for each medicine.

Given MedAdvisor knows my prescription now, it can actually tell me when it's time to re-fill my supplies. Since my transplant was relatively recent, my dosages still vary somewhat, so, for example, I take less Prednisolone than my prescription says, so MedAdvisor thinks I am running out but I still have plenty left. If your dosages are stable, MedAdvisor can take over pill stock level management from MediSafe App, described earlier.

The same applies for an Oxymeter, one of those things you clamp on your finger and it shows my blood oxygen levels. I have one of those too, from iHealth, so the same App that records my blood pressure can also connect to the Oxymeter.

Finally, for a short period after my transplant, I had drug induced diabetes. I had to monitor my glucose levels at various times during the day. For those of you that have permanent diabetes, this also applies.

My glucose meter is able to connect, via bluetooth, to an App in my phone. Measure my glucose and bang, the meter connects to the phone App and the levels are there. Date, time, level and if I could be bothered, a note, maybe indicating that I had just eaten breakfast. At the time of writing, I no longer have diabetes and do not monitor my glucose levels. Still, the App is able to talk to Apple Health, upload the glucose recordings for examination by my GP, should it be required.

So that's it, my phone now has all my medical information, I can share with my doctor easily, no more faulty memories, forgetting the Blue Book, forgetting this pill, not knowing blood pressure, etc.

My phone is an iPhone, it has an 'emergency' mode which allows medical personnel to see my medical information, so that if I am unconscious, they can still give me appropriate treatment. I assume an Android phone has a similar capability.

So, there really is "An App for that".

Best of health.

Lyall Pearce
Heart transplant 1 July, 2020

FACT

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

VALE

The community of Transplant Australia are deeply saddened at the passing of Roxanne Kavanagh on November 8.

Roxanne was involved for many years and in so many ways with the transplant community.

She was full of vitality, positivity and enthusiasm in everything she put her mind to – as Chair of the Transplant Australia Victoria Committee, assisting with events and the Victorian team at the Transplant Games and always there to offer care and support to participants at the national and world transplant games. Roxanne was also heavily involved with The Alfred Hospital; fundraising and visiting transplant recipients in need of guidance and support.

A person of great integrity and strength. Roxanne was a joy to be with – playful, smart, funny, sincere and compassionate – direct, yet always, mindful of everyone's feelings.

Roxanne received a double lung/heart transplant over twenty years ago. She was so grateful for her gift of life. Even in the past couple of very difficult months, Roxanne could always see a funny side, be philosophical and so grateful for the life that she had been able to live.

Roxanne was truly a wonderful role model for both new and long-time recipients.

Information courtesy

transplant australia
make the most of life.

I am super proud of myself for facing COVID head-on and coming out the other side.

Heart transplant recipient v COVID

Everybody's experience with COVID is unique, my dog Louis got me through mine!

By Nicole Constantinou | *Heart transplant 18 June, 2018*

September 4th, 2010 is a night neither my family nor I will ever forget. I was an active and healthy 20-year-old getting ready for a night out on the town when I suddenly went into cardiac arrest.

Years of unexplained fainting spells and many trips to emergency, being told that I am 100% fine, were finally clarified when I was diagnosed with a rare condition called Long QT Syndrome. Long QT syndrome is a hereditary condition that causes fast, chaotic and in some circumstances, fatal heart arrhythmias.

I came out of that ordeal relatively unscathed, internal defibrillator in tow and with some heart medication, my cardiologist sent me on my way.

I lived a semi-normal, yet extremely anxious life for the next seven or so years until my body became accustomed to my medication. I suffered many internal defibrillator shocks – 74 that I managed to count (ouch!), but it was all too much for my body to tolerate and I once again, went into sudden cardiac arrest, but this time, with my internal defibrillator.

Following this event, my cardiologist decided that my heart was simply too unstable to lead a normal life and that I should consider a heart transplant.

Terrified and traumatised by my life thus far, I decided to go through with the work-up process to see if I was eligible.

I spent 10 days at St Vincent's Hospital in Sydney, undergoing endless tests until I was finally deemed an appropriate candidate for transplantation and sent home to Adelaide to await my life-changing phone call.

Eight months, two false alarms behind me, a proposal, the birth of my niece, and a new kitten later and I was finally wheeled into theatre and given the greatest gift I have ever received, a beautiful new heart and my life back.

Fast forward three years, lots of rehabs, countless medications, and never-ending doctors' appointments, I was finally happy and healthy with only one little thing standing in my way – a global pandemic!

The COVID-19 pandemic ignited a fear in me that I hadn't quite felt since my transplant.

As a transplant recipient, my full-time job since 2020 had been to avoid catching COVID. I took it upon myself to make my health a priority and take every precaution possible to avoid catching the virus. I got double vaccinated, I began studying my degree full-time from home, ordering our groceries online, sanitising our clothes, wearing masks, and avoiding busy restaurants and high traffic areas became my new normal.

Seeing the hike in case numbers across Australia gave me extreme anxiety and unfortunately, I knew it was only a matter of time until I would contract it.

2022 rolled around and I was super proud of myself for managing to avoid catching COVID those past two years and my new year's resolution was simple – don't contract COVID. I managed to stick to my resolution for approximately 7 days as by the end of the first week of the new year I tested positive, just my luck!

In my defence, who keeps their new year's resolutions anyway?

My first symptom popped up on a Friday night. I couldn't quite figure out why I felt exhausted from having a relatively lazy day consisting of a trip to the dog park, a quick food shop and a Disney marathon with my nieces.

I went to sleep early and woke up Saturday morning (day 1) as though I'd been hit by a truck. Body aches beyond belief, throbbing headache, high temperature (38.9°C), chills, and dizziness were the first symptoms to rear their ugly head.

Barely able to keep my eyes open, I drove to my nearest COVID testing site and had a PCR test, drove home, took two Panadol, sculled a Powerade and went to sleep until the following morning.

Sunday (day 2) was much worse, I somehow managed to shower after a very sweaty night, the symptoms from Saturday were still present but I was much weaker and had no appetite. Again, spent the day in bed with an occasional trip to the fridge for water and a Panadol top-up.

I managed to get my hands on a Rapid Antigen Test (RAT) and tested positive almost immediately. My bedside table now consisted of empty Panadol packets, my transplant medications, jugs of water, Sustagen, tissues, butter menthols, my trusty thermometer, and a pulse oximeter (which my fiancé swiftly confiscated from me because I became unhealthily obsessed with it).

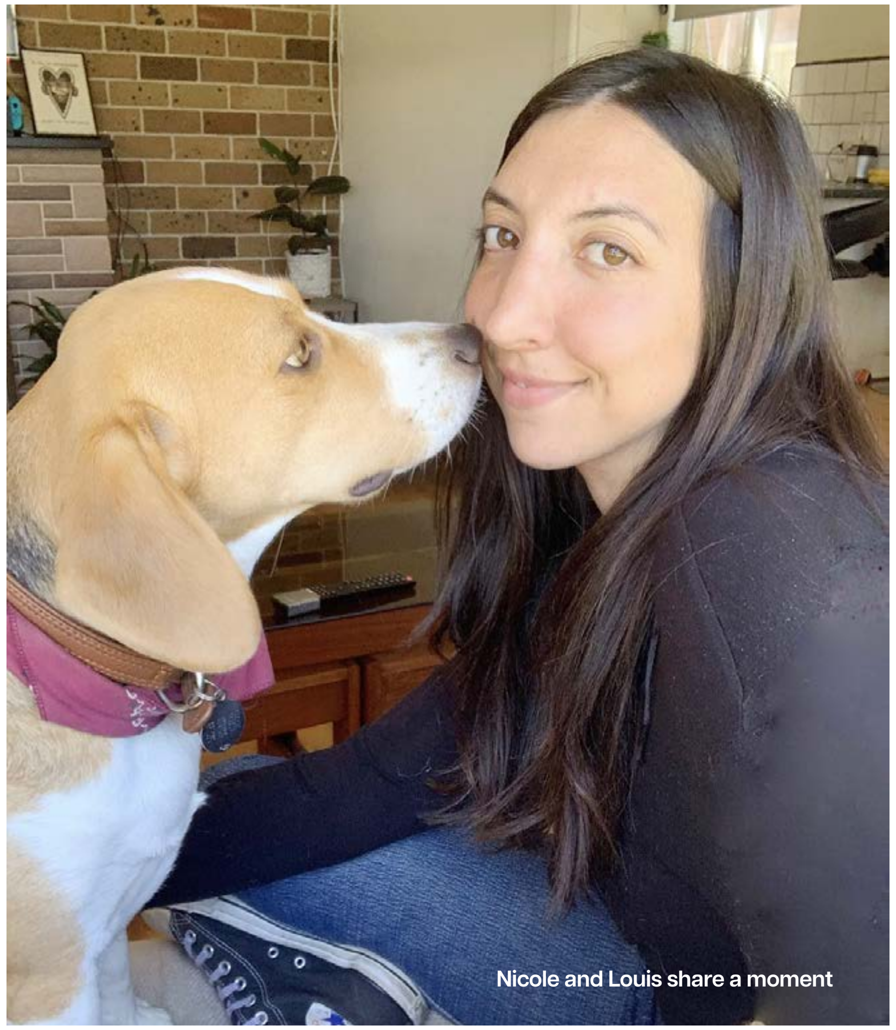
I was now certain it was COVID, therefore first thing Monday morning I nervously contacted my transplant team at the Royal Adelaide Hospital. They assured me that I should be okay but to call an ambulance right away if I noticed a decline in my breathing or if my symptoms became unbearable which luckily, they didn't.

I quickly confided in my fellow transplant recipients for support which was when I was told about an antibody treatment that could potentially be helpful. I spoke with my doctors about this and they agreed that the infusion would be beneficial for me. I was told I needed a positive PCR test result back before I could have this treatment but the return times for PCR tests were relatively high therefore it was not until Wednesday that I was able to enter the hospital as an outpatient for the treatment.

On Wednesday morning (day 5), I was conveniently picked up by an ambulance transport van and transported to the RAH along with two other COVID positive patients who needed treatment. We were required to wear face shields and masks for our entire session at the hospital and were very well taken care of by the nurses working tirelessly to treat the insane surge of patients that followed.

I was seen almost instantly and had my blood pressure, oxygen levels and heart rate swiftly checked, and I was then given a brief run-down of what the infusion was and what to expect afterwards.

The antibody infusions official name is 'Sotrovimab' and is given intravenously. Only a single dose is required, and it is recommended for anyone who is deemed to be at high risk of hospitalisation or death due to COVID.


Nicole and Louis share a moment

It is recommended that this infusion is given within 5 days of showing symptoms and an official diagnosis.

The infusion lasts for 30 minutes but the patients are required to stay at the hospital for monitoring for one hour post. At this time, I was given a bag of fluids as I was severely dehydrated. To my surprise, I noticed a change in my symptoms almost instantly. Not sure if it was the infusion, the bag of fluids or the sweet taste of freedom I experienced for that few hours of being out of the house, but I noticed a spike in my energy levels, I felt hungry- which I hadn't felt in days and my temperature had dropped.

The following days I started to feel increasingly better with my symptoms still very much apparent but nowhere near as severe as they had been. By Friday (day 7) my only remaining symptoms seemed to be extreme fatigue and low appetite, I was still sleeping for the majority of the day but I was now able to eat full meals, keep fluids down successfully and have a little walk around the house and backyard without becoming out of breath.

To my surprise, I woke up on day 8 with a tingle in my throat and a slight cough which was upsetting as I was sure my symptoms were improving by this stage. I continued with the Panadol and plenty of fluids and luckily these symptoms did not progress further.

By day 9 and 10, I was feeling extremely agitated and slightly anxious about my sore throat and cough. Though it was bearable, I worried that it would get worse and potentially affect my breathing which luckily did not happen so I contacted my transplant team, and they swiftly eased my mind and explained that this is a normal symptom to COVID and to keep up with fluids.

Day 11 was my official 'Freedom Day' which I felt beyond excited for – mostly so I could take my dog for his long-awaited walk – but I was still slightly symptomatic so decided to keep my family and community safe by staying home until I was no longer feeling evident symptoms.

Luckily the following day (day 12)
I woke up feeling much better and felt comfortable enough to visit my immediate family.

I still experienced some lingering symptoms such as fatigue, loss of smell and a slight cough for another couple of weeks, but I am super proud of myself for facing it head-on and coming out of the other side.

Just another sickness that I have been able to overcome, and I couldn't have done it without my transplant doctors, my fiancé, my transplant friends for their ongoing support, the nurses who worked tirelessly for us and most importantly – my dog Louis who never left my side.

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 and the Heart & Lung Transplant Trust of Victoria 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's transplant program | **www.hlttv.org.au**

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.

Visit us at www.hlttv.org.au

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

The essence of humanity

A donor's organs don't discriminate on the of basis race, colour or creed, why should the recipient?

The Apple consultant in the Philippines noticed the story I was writing as she joined me on screen-share, in order to solve my computer problem. Explaining succinctly the gist of the story line, as requested; the interest from this young Filipina, working from home in searing heat in the thick of her COVID-19 ravaged homeland, was palpable.

My story, still in the initial stages when my computer problem interrupted, talked of the recent Middle Eastern conflict. The fragile ceasefire agreed to by Israel and the Palestinian militant group, Hamas just weeks earlier on May 21, had already been broken. I was writing about the incredulity of the continuing violence in the Middle East, whilst simultaneously we battle a global pandemic causing havoc and heartache.

Not yet written, I went on to relay to the tech consultant the sorely needed good news story coming from the conflict zone I'd read of in The Australian Jewish News (4/6/21).

The article, "Kidney Donation, A symbol of hope" reported an event, more powerful than any peace talk could possibly be.

A Jewish man, killed by rocks pelted by Arab rioters, had become an organ donor. His liver and a kidney had been donated to fellow Jews. Whilst poignantly, in life saving surgery his other kidney, was received by a Christian Arabic woman who urgently needed a transplant. The recipient and her profoundly grateful family had made contact with the donor's wife (as permitted in Israel).

The families, hoping to meet will come together and be bonded for a lifetime through this ultimate act of selflessness and generosity, the greatest gift of altruism in the face of suffering and need. In the words of the recipient, "We are like family now", appealing for "peace between Jews and Arabs."

This is not the first such transplant between Arab and Jew. The story of a 19-year-old Scottish Jewish student, killed in a Palestinian suicide bombing in Tel Aviv in September 2002 whose kidney went to a Palestinian child, has never left me. Some time after the transplant the mother of the donor visited the young recipient and her family. The mothers hugged for a long time, embraced in something more powerful than words.

A week after reading the story of the recent kidney transplant, there was another article in The AJN (11/6/21) which illustrated again the potency of human kindness and connection in the face of hatred and barbarity. "David Dushman, Last Auschwitz liberator mourned" told of the meeting decades earlier between this 98-year-old Jewish Red army soldier who'd become an international fencer, and Thomas Bach, International Olympic Committee president, who happened to be German. Bach commented on the "friendship and counsel" offered to him in that meeting past, despite Dushman's Jewish identity and wartime experiences. For Bach "This was such a deep human gesture that I will never forget it."

At the end of my Apple call, computer problem rectified, the consultant was quiet; this story of deep empathy in the midst of darkness from the other side of the globe, she told me, had moved her deeply and given her hope. She would face each day with a little more strength and equanimity, trusting that her world would one day return to some sort of normal.

Later, reflecting on my long-distance conversation with this stranger, I welcomed the opportunity to provide a review on my Apple enquiry, as the request appeared on my screen. A brief encounter between a young woman, defying the odds to stay safe and make a living, with an older woman surrounded by the relative comfort of life in Australia.

Connection, empathy, kindness to our fellow man, regardless of race, colour or creed, as the transplants reflect, are the essence of humanity.

By Janine Joseph
Melbourne writer

This is an edited version of an article that was previously published in *The Australian Jewish News*

FACT

All major religions support organ and tissue donation

Finally, Len got to have his celebration

Turning 80 is a significant milestone, especially if you've had a lung transplant almost two decades prior.

Len Hain had planned to celebrate his 80th Birthday in July 2020, but due to COVID restrictions in Victoria the date was changed to November, being the 18th Anniversary of his Lung Transplant.

COVID restrictions were once again in place and the celebration had to be postponed. 2021 proved difficult because of restrictions and so 16 January 2022 was chosen.

Len's wife Nicole is well known for organising a feast when they entertain but this time they decided to have caterers and who better than a friend who has a Vietnamese Food Van. So with waiters and an entertainer (Guitarist) it was a most enjoyable day – taking place in the shade of their beautiful garden on a perfect summer day in Melbourne.

It was a very special time for Len and Nicole as their son and his family travelled from The Netherlands and their daughter and family came down from Northern NSW. It was the first time they had all been together in three years.

In his speech Len reflected on how lucky he was to be celebrating such a special occasion with so many of his longstanding friends – some in excess of 70 years, work colleagues, business associates and other transplant recipients who he had met along his journey and now counts as friends.

But of course it has been with the love of his family and particularly Nicole who without her support he would not have been able to reach this milestone. She has been beside him all the way no matter what the circumstance.

Lastly, in addition to toasting enduring friendships, Len specifically included all the unknown organ donors without whose generosity he would not have been able to celebrate this milestone.

In lieu of gifts, guests were asked if they would care to make a donation to the Heart and Lung Transplant Trust of Victoria.

An amount of $1682.00 has been generously donated to the HLTTV.

Even after a bout of COVID last year, Len keeps going strong and is now 83 and celebrated his 20th Transplant Anniversary in November 2022.

Getting out of your comfort zone

I have never really been into crafts but have a friend who is amazing at drawing, painting, ceramics, jewellery making and basket weaving, just to name a few.

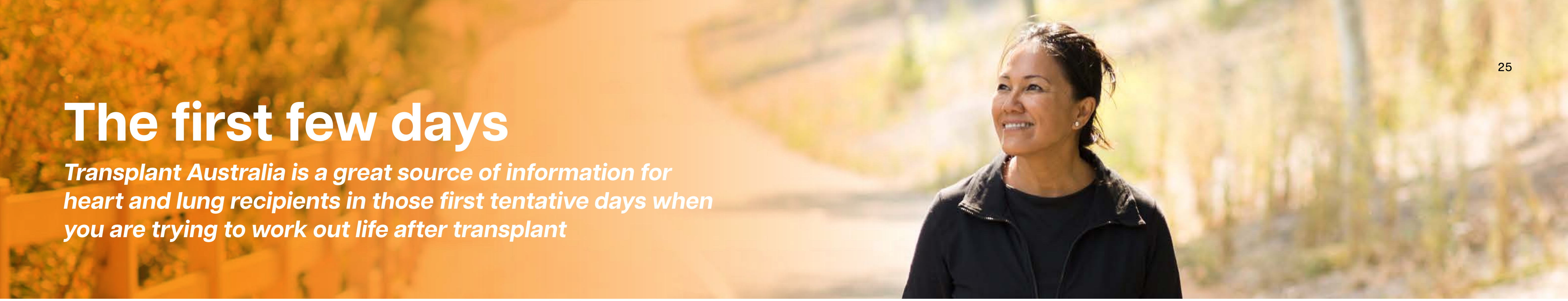
She always suggests I come along to a class and somehow I gave in and attended her basket weaving class – the perfect setting at a Nursery on a beautiful day.

I came away with two pieces of work which was really nice. The two other participants (who didn't know each other) were nurses. One of them told me that her husband had a kidney transplant when he was quite young and now was on dialysis.

They were both happy to see that I was going well with my heart transplant.

Is it time to get out of your comfort zone? I'm sure you will meet some interesting and lovely people.

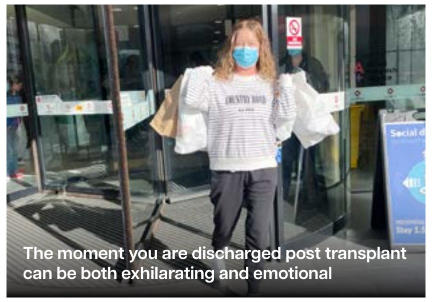
By Gaylynn Pinniger
Heart transplant 23 Dec, 2002



The first few days

Transplant Australia is a great source of information for heart and lung recipients in those first tentative days when you are trying to work out life after transplant

The following information from **Transplant Australia** covers some of the big questions recipients face such as: what are the most significant side effects from transplant medications, what organ rejection looks like and whether or not to contact your donor family.



The moment you are discharged post transplant can be both exhilarating and emotional

Hospital stay and discharge

As you start healing, walking a little more each day will help facilitate your recovery.

Immediately after your transplant, you will be monitored carefully. The average stay in the intensive care ward is 2 – 3 days, but may vary depending on your condition. Typically, your stay in the hospital may last between 1 – 4 weeks.

After leaving hospital, your transplant team will review your progress and fine-tune the medications you'll take to keep your transplant safe. This means you will have to set aside time to return to the clinic frequently (in some cases daily) to undergo blood tests and health checks.

Travelling long distances for frequent follow-up treatment can be expensive for those who live far away from their treating hospital. Patient travel assistance schemes can support you during this difficult time. The frequency of these visits will most likely decrease within a month. After one year, you may only need to visit your clinic every three months.

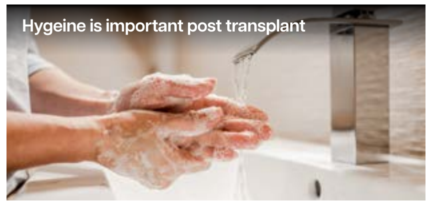
Recovery

A combination of drugs called anti-rejection drugs or immunosuppressants will care for your organ throughout the life of your transplant. These medicines suppress the immune system so your body can accept the new organ, and control rejection.

A suppressed immune systems means you'll have to carry out everyday activities more carefully than other people so that the new organ is safe and your quality of life is maximised.

High blood pressure, increased fat in the blood (cholesterol levels) and fluid retention are some of the side effects of the medications and you may need additional drugs to manage these.

Initial doses of transplant medication can also cause tremors, weakness and blurred vision. With time, these symptoms may settle down as the doses reduce and your body adjusts to the immunosuppressants.



Hygeine is important post transplant

Things to consider while you heal

1. A low immune system makes recipients more vulnerable to infections. You can pick up infections from your surroundings, through contaminated food and water or even from pets. Protect yourself from food-borne illnesses by preparing, handling and storing food safely.

   Unpasturised milk, untreated water or undercooked meats, fish and eggs may cause life-threatening infections.

2. Some transplant medications which get processed in the liver can interact with alcohol and cause liver damage.

   As your body is adjusting to the new organ, it is advisable to refrain from drinking. Once your medication regimen has been established, you will be able to enjoy a wine, spirits or a beer.

   To be safe, check with your doctor before you start consuming alcohol. Be aware that it can cause weight gain and a rise in blood pressure. For more information on recommended alcohol consumption for transplant recipients refer to www.transplant.org.au

3. Smoking dramatically increases the risk of developing lung cancer in recipients. It damages the lungs, making you vulnerable to infections including bronchitis, emphysema and pneumonia.

4. Immunisations using live bacteria or viruses are hazardous as they can activate in your body. Mantoux tests for tuberculosis and immunisations for yellow fever are forbidden. Always check with your transplant doctor if you are advised to take immunisations by another doctor or before you travel overseas. For immunisations that are safe for recipients refer to www.transplant.org.au

5. It's not advisable to lift anything heavy for at least 8 weeks after surgery. Consult your transplant doctor to clarify the maximum weight you can carry or before starting any weight training exercises.

6. It is advisable not to drive in the first few weeks after surgery while the impact of the immunosuppressants are most pronounced. Most recipients are able to resume driving within 6 – 8 weeks.

Common post transplant infections and how best to avoid them

The risk of catching infections is highest in the first 6 months. Surgical wounds and the chest are the most frequent sites of infection.

Common infections to look out for:

Golden Staph, a bacteria commonly carried in the skin or nose of healthy people, is generally harmless. However, if this bacteria enters the body though a cut or wound, it can cause mild to severe infections. Golden Staph is spread through skin-on-skin contact; by using contaminated objects (door knobs, telephones, television remotes, elevator buttons, contaminated food), or inhaling infected droplets dispersed by coughing or sneezing.

A staph infection can manifest on the skin (boils and abscesses) or in the bloodstream. Swelling or redness on the skin, or a temperature above normal can be indicative of an infection.

Protect yourself by washing hands thoroughly with soap and water or with antibacterial gels, and covering exposed wounds. Mild cases of skin infections can be treated with antibacterial ointments while more severe cases can be managed with antibiotics.

Pneumocystis (PCP) is an organism that doesn't affect healthy people. However, this can cause a serious form of pneumonia in recipients. Treatable with antibiotics, PCP causes cold and flu like symptoms, tightness of chest, coughs, weight loss and elevated temperatures. Transplant recipients are prescribed antibiotics (Bactrim or Resprim to be taken twice a week) as a preventative.

Herpes virus infections like **Cytomegalovirus (CMV), Epstein Barr Virus (EPV)** and **Herpes Simplex Virus (HSV)** are a risk to recipients. They remain dormant in healthy bodies and can reactivate when the immune system is suppressed. There is a high chance of these viruses becoming active after surgery if either you or your donor have been exposed to it at any time in your lives.

CMV symptoms include temperature spikes, loss of appetite, lethargy, abdominal pain and diarrhoea. EPV indications include sore throat, swollen glands, fatigue, fever, lack of appetite, rash, weakness and sore muscles.

Cold sores usually appear on the lips and can spread into the mouth. If you notice sores or eruptions on your lips, you must inform your doctor at the earliest opportunity to commence antiviral treatment.

Your doctors will assess you for risks associated with EPV/CMV. Gancyclovir is commonly used in the prevention or treatment.

Emotional changes at a glance

Life after transplant will have new challenges and successes. Recipients have reported feeling relieved and elated after the success of their surgery. With time though, initial optimism may be tinged with other feelings.

You may start to worry about your condition coming back, or for the safety of the organ. Medications may cause emotional highs and lows. Recipients have described feeling irritable and disinterested in activities they used to enjoy before.

Stress about commencing/returning to the workforce is common. Illness and organ failure often force recipients to take a break from employment. Integrating at the workplace, picking up a high-stress job, remaining safe from infections, juggling frequent medical appointments and health issues can be a worry. Part-time work or opting for less stressful roles helped some recipients ease into their jobs.

Connecting with other recipients is a way to gain emotional support during recovery

Reflecting on the donor and feeling guilty about benefiting from their death; feeling bound by a sense of obligation to the donor for a new lease in life are common thoughts too. These thoughts can manifest into feelings of pressure.

Meeting other recipients at events like the Australian Transplant Games can be beneficial. Sharing experiences/feelings with people who face similar circumstances was reassuring for many recipients. For others, communicating with the donor family helped.

Consult your GP if you or your carer are concerned about your moods.

Relationships and sex

Reengaging with friends and family will help you move on. The emotional stress of illness and surgery may have put a strain on your close relationships. Reconnecting with your partner and resuming your sex life is critical for recovery.

Sexual activity will not harm your transplanted organ, although external and internal wounds need to heal before resuming any vigorous activity. This usually takes between 4-8 weeks depending on the type of transplant.

Article continues on next page...

Some recipients find an improvement in sexual function and desire post transplant. However, some medications may lead to weight gain, acne, bruising and increased body hair, which can cause recipients to feel unattractive and less interested in sex. Recipients may also experience a loss of libido (some blood pressure medicines can cause this). Speak to your doctor who can suggest alternative medications to reduce these side effects.

Safe sex for transplant recipients: If you're single or starting a new relationship, be aware that recipients can catch STDs more easily due to a low immune system. Protect yourself from sexually transmitted diseases by using condoms and report genital rashes, sores, unusual discharge or yeast infections immediately.

Women on immunosuppressants are more prone to urinary tract infections than men because of the proximity of the vagina, anus and urethra. This makes it easier for bacteria to reach the bladder. To remain safe, it's important to empty your bladder before and after sexual activity, and wipe from front to back after bowel movements.

Pregnancy: When it comes to pregnancy, every recipient is different. It takes time (usually 1-2 years) for the medication regime to stabilise and the transplanted organ to function well. It's advisable for women to ensure they are healthy enough to have a baby and avoid the risk of rejection before they decide to grow their family.

Many recipients have successfully become parents. You need to speak to your doctor if you are considering having children as some immunosuppressants can be harmful to the unborn child. Your physician will be able to change your medications and recommend ways of having a safe pregnancy.

To avoid unwanted pregnancies, discuss birth control options with your transplant doctor. Condoms, diaphragms, and spermicidal jellies are usually safe for recipients to use. However, some contraceptive pills can interact with your medications. Check with your doctor for a product that is suitable for you.

Donor families and living donors

Communicating with the donor family

Transplant recipients have the opportunity, through their transplant coordinator, to communicate with the family of their donor to express their thanks and appreciation. To the donor family this may bring comfort and help them through their bereavement.

Writing a message to your donor is a way to express your gratitude to their family

Because it's sometimes difficult to put into words expressions of gratitude, transplant recipients can ask their transplant coordinator or social worker for help to write their message. In addition, Donatelife has prepared Correspondence Guidelines for transplant recipients to write to their donor families.

Keep in mind that the donor family has suffered the loss of a loved one and may choose not to respond immediately, or at all. In turn, some transplant recipients choose not to communicate with their donor families at all, or sometimes much later, at a time that feels right for them.

Donor families can, and frequently do, request updates through Donatelife about transplant recipients' wellbeing. The identity of the donor and recipients are kept anonymous to maintain privacy. For more information on donor-recipient contact, visit DonateLife.

The Donatelife agencies conduct Services of Remembrance throughout Australia to acknowledge the generosity of donors and their families, and provide an opportunity for transplant recipients to show their gratitude.

Living donors

Just as donor families make the important decision for their loved-ones to become donors, living donors make one of the most immense decisions of their lives to donate. In both cases, it is a gift by choice to transform the life of another.

To honour this ultimate act of giving by donor families and living donors, transplant recipients can show their deepest appreciation through written and spoken words of gratitude; by living life to the full and taking great care of themselves to ensure that their transplant has every possible opportunity to thrive.

Transplant Australia endorses the support programs that are offered for living donors through such organisations as Kidney Health who provide a Kidney Health Information Service to answer any queries that potential living donors may have.

The Australian Department of Health offers the Supporting Living Organ Donors Program to assist with reimbursing expenses incurred as part of the donation process.

Changes in your food after transplant

After your transplant, you will have a lot more freedom with your diet. During the first few days, you may need to continue to limit certain foods. Your dietitian or medical team will let you know if this is necessary.

It is important that you try to eat well during this period to help your wound heal. Engaging in regular physical activity and maintaining good nutrition will also reduce some of the side effects of your medications like:

- increased blood pressure
- increased cholesterol
- increased blood sugar level
- weight gain
- weak bones and osteoporosis

Protein

Studies that show that transplant recipients may need a high protein and energy intake temporarily after their operation. Protein-rich foods include meat, chicken, fish, eggs, dairy products, nuts, legumes and lentils. Once your wounds heal, protein requirements are no longer as high.

You will need to regulate your protein intake depending on the type of transplant you've had. For example, if you are a kidney recipient, your protein must be monitored to ensure the new kidney has less work to do while processing meals.

Phosphate, Magnesium, Potassium

Our body depends on minerals like phosphates, potassium and magnesium to maintain some of its functions. Organ failure, or the treatment of the disease leading to organ failure, can lead to an imbalance in some of these minerals.

Examples of how mineral imbalances can affect us:

- Found in many foods we eat, potassium plays a key role in muscle contraction and heart function. Kidney failure causes a buildup of **potassium** in the body causing fatigue and nausea. Very high levels of potassium can be dangerous for the heart
- Some medicines used to manage heart failure can cause a loss of potassium. Low potassium levels can cause muscle weaknesses and heartbeat irregularities
- Magnesium is essential for several body functions including muscle health. People with cirrhosis of the liver often have depleted levels of magnesium. Anti-rejection medications taken after your transplant can also deplete magnesium levels causing muscle cramps and fatigue
- The balance of calcium and phosphorous, vital for bone health, is maintained by the kidneys. An imbalance in these minerals caused by kidney disease can lead to bone diseases. High doses of immunosuppressants administered during initial weeks after transplantation can also cause weak bones

After transplantation, the levels of these minerals will be monitored every day. Your doctor will advise you (based on the results of blood tests) to increase or restrict any of these minerals.

The foods that we eat every day are the main sources of phosphates, magnesium, calcium and potassium. Talk to your dietitian regarding foods that contain these minerals. You can easily meet your daily requirements by including healthy options in your daily meals.

Widely used as preservatives, phosphates are found in processed cheeses, parmesan, cured meats (ham, bacon), colas, packet soups, vegemite, baking powder (biscuits, cakes and pastries) and fast foods. Limiting these foods or choosing healthy options from the above table will help you balance your mineral levels, and keep your transplant safe.

POTASSIUM	CALCIUM	MAGNESIUM	PHOSPHATES
			
• Nuts • Fresh fruits and vegetables • Milk yoghurt • Wholemeal or wholegrain breads and cereals, wheat/oat bran	• Dairy products such as milk, cheese, yoghurt (beware of fat content) • Almonds, dried figs, apricots • Dark leafy green vegetables, broccoli, bok choy, okra, cabbage, cucumber, celery • Legumes like white beans; edamame	• Green vegetables like spinach, broccoli, green Chinese vegetables, leeks, zucchini, peas, cabbage, asparagus • Wholemeal or wholegrain breads and cereals; wheat/oat bran • Legumes and dried beans; nuts and seeds; soymilk • Seafood and fish	• Lean meats, chicken, eggs and fish • Cheese, yoghurt, milk, soymilk, custard, ice-cream • Wholemeal and wholegrain breads and cereals, wholemeal pasta • Legumes and dried beans • Nuts and seeds

Check out the table above for some healthy foods that are high in these minerals.

Blood glucose levels

As your appetite returns, you'll be able to eat a variety of foods that were restricted before. Your medications may make you very hungry. Recipients can gain weight rapidly in the first year. This weight gain is sometimes difficult to get rid of – however, by being mindful and prepared, you will be able to combat this.

Weight gain can lead to heart disease and diabetes (high blood sugar levels). Recipients may also experience high glucose (sugar) levels within the first few weeks as a result of immunosuppressant therapy.

You can manage your calorie intake and blood sugar levels by:

- Opting for low-calorie meals
- Replacing high-calorie foods with raw vegetables and fruit, whole grains, lean meats and skinned poultry, nonfat dairy products and low-calorie or sugar-free beverages
- Eating regularly-spaced meals (do not skip meals)
- Avoiding sugar-rich foods like lollies, chocolates, cakes, biscuits, soft drinks, fruit juices

Ensure your diet includes plenty of calcium-rich foods as you will be prone to **bone-thinning and osteoporosis**. This may occur over the first few months when doses of your medications are at their highest. Often there are no symptoms for thinning bones. You may have to undergo a **bone mineral density test** to detect this.

Glucose Levels

If you've had a lung transplant due to cystic fibrosis, you may be on CREON.

It is important to continue taking it with your meals. An improved respiratory function will help conserve more energy. With less calories to burn, you'll be able to maintain your weight with smaller food intakes.

Understanding rejection

When you have a transplant, your immune system identifies the new organ as a foreign body and tries to reject it. This is a normal immune response.

In order to control rejection, you'll be given a combination of medicines to suppress your immune system and stop your body from attacking its new organ.

These medicines are called immunosuppressants or anti-rejection drugs and must be taken for the **entire life of your graft.**

After transplant it's not unusual to experience one or more episodes of rejection during the recovery period. These can be controlled in most cases by medication.

This is a risk you will need to be aware of throughout the life of your graft. **The onset of rejection does not mean your organ will be lost, but prompt treatment is critical.** The symptoms of rejection depend on the type of transplant you have.

Symptoms of rejection

After your transplant you need to look out for fatigue, lethargy, a feeling of illness

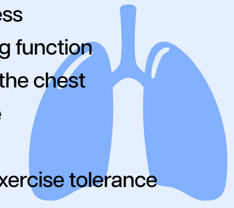
Article continues on next page...

or lack of apetite. There are specific symptoms for each type of transplant:

HEART transplant rejection

- Swollen ankles
- Palpitations
- Shortness of breath
- Lightheadedness and dizziness
- Decreased exercise tolerance

LUNG transplant rejection



- Breathlessness
- A drop in lung function
- Tightness in the chest
- Temperature
- Cough
- Decreased exercise tolerance

Treatment for rejection

Rejection is quite common in the early stages following a transplant. It can occur any time but most commonly takes place within the first 6 months. Rejection may be mild or acute, and in most cases can be controlled if treated promptly.

Many episodes are picked up by blood tests during outpatient visits. A biopsy may be required to make a definitive diagnosis. During a biopsy a sample of the transplanted organ is collected and examined under a microscope, and the results will determine if a change in treatment is required. Doses of existing medications may increase or decrease, or a new medication may be recommended.

The dosage of immunosuppressants depends on your condition and may be very high while the tissue is being rejected. The goal of treatment is to make sure the transplanted organ or tissue works properly, and to suppress your immune system's response.

After you no longer have signs of rejection, the dosage will likely be changed.

Medications

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

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

Missing even a single dose or stopping the medicines without guidance from your doctor can put your organ at risk. The amount of medications will reduce over time, but you will have to take them for the rest of the life of your transplant.

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

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

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

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

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

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

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

Call your doctor if:

- You cannot take your medicines by mouth for any reason
- You think you're having a reaction to the medication or have any unusual symptoms
- Medication from the pharmacy looks different than the medication you had before
- You're not sure what dose to take. Doses can change frequently and may not be the same as what is printed on the label
- If a doctor (other than your transplant doctor) prescribes a medication
- You need to take medications for pain relief, cold and flu medicines or any other over-the-counter medications. Also seek approval before you take any aspirin or non-steroidal anti-inflammatory drugs

You can find information on your medication at the **Therapeutic Goods Administration website.** Enter the trade name or the active ingredient in your drugs to learn more.

Taking medication with or without food

You might have noticed stickers on some of your medications that say "Take on an empty stomach" or "Take with food." It's important to understand how food impacts the way drugs work so you get the most out of your treatment.

When you swallow a medicine, it gets absorbed by the body and the amount absorbed depends on whether your stomach is full or empty. Therefore certain medicines should not be taken with food. The food in your stomach can **delay** or **decrease** the amount of drug that is assimilated in your blood. If the amount of anti-rejection medicine absorbed is less than expected, there is a risk of organ rejection.

Some medicines need to be taken with food to work better and cause less side effects, e.g. it is recommended to take prednisone with food. On an empty stomach, the drug may irritate the stomach lining and cause stomach upsets.

Your transplant team will give you information on when is best to take each medication. It's important to take your medicine in the same way each time, so that the amount absorbed will be consistent.

Why you need to take your medication at the same time each day

When medicine is taken, the amount of drug absorbed in the blood increases to a peak, then decreases over time. The drug concentration in the blood must be high enough to produce the desired effect, but low enough so as to not cause too many side effects.

The times prescribed for taking anti-rejection drugs are carefully scheduled so there is always enough drug in your body to prevent rejection of the transplanted organ. You should take your anti-rejection drugs at the times agreed by your transplant team **to ensure the correct amount of drug is in your blood at all times.**

Side effects

You will be prescribed a balanced regime of anti-rejection medicines so that side effects are minimised while preventing organ rejection. The severity of symptoms differ in each patient. You must report anything untoward to your transplant doctor or nurse. Remember that not everyone gets these side effects.

You may also find symptoms reducing over time as the doses of your medicines are cut back.

Consult your transplant team and GP about the side effects that you may encounter with the specific medications you are taking.

Over the counter and generic medications

You may often hear about generic medications. Similar to the medicine your doctor might have prescribed, 'generic medicine' is a common term used when there is a less expensive brand of medication available.

The amount of active ingredient in the generic medicine, purpose of its use and administration would **be the same** as the brand on your prescription. The generic medication can vary in the ingredients used to bind the formulation and in the way it's manufactured.

In a complex medication regimen for an organ transplant it is recommended that you **do not substitute** between brands of medications with the same active ingredient.

If your pharmacy dispenses a medicine that looks different than before, call your transplant doctor and ensure it's safe to stay on the same dose. Your blood levels may need to be monitored if you switch manufacturers.

Nonsteroidal anti-inflammatory drugs (NSAID) can interact with transplant medication and cause serious health hazards. Unless specifically advised by your doctor, do not take aspirin or anti-inflammatory drugs like ibuprofen as they may cause stomach irritation and kidney impairment.

Check with your transplant doctor before taking any over-the-counter medications like cold and flu tablets and anti-diarrhea medicines, as they could hide more serious conditions that should be investigated.

Storing your medicine

✓ Store in a cool dry place away from direct sunlight

✓ Moisture can cause harmful changes medicine. Do not store your medicines in the bathroom or in an area where moisture levels are high

✓ If you're using a pillbox, keep it tightly closed

✓ Retain your transplant medications (e.g. cyclosporin, tacrolimus, everolimus, sirolimus) in their foil packs or blister packs until ready to take them

✗ Do not crush or cut tablets, capsules and caplets unless instructed

✗ Do not store them in the refrigerator unless instructed

✗ Do not freeze liquid medications

✓ Keep them away from children, pets or animals.

Over the counter and generic medications

Beware of what reacts with your drugs. What might be good for people who haven't had a transplant might not be good for recipients. Check with your doctor before commencing any new medication.

Drug

Whether you are prescribed a short-term course of medicines (i.e. antibiotics) or are treated for another chronic condition (long-term therapy), be aware of interactions with your anti-rejection medications. For example, there are many drugs that may cause the cyclosporin or tacrolimus level in the body to change significantly.

Some antibiotics such as erythromycin, roxithromycin, fluconazole can lower the amount of anti-rejection drug in the body causing a high risk of rejection, whilst drugs such as rifampicin, St John's Wort and phenytoin can cause high levels of drug to remain in the body, increasing the risk of toxic side effects.

Food

Check with your pharmacist to determine foods that you need to avoid or restrict whilst taking transplant medication, as they may interact. A common fruit for recipients to avoid is grapefruit and products containing grapefruit.

Chemicals present in grapefruit can affect the way transplant medications are absorbed in the body. If you're taking tacrolimus, grapefruit can increase the tacrolimus levels in your body leading to potentially dangerous side effects.

Superfoods like goji berry, spirulina and kale have not been tested as yet for interaction with transplant medication and must be consumed with caution.

For more on eating to keep your transplant safe, check out our **transplant-friendly recipes.**

Herbal remedies

There are many herbal supplements available, often marketed as cures for illnesses. While some herbal medicines can be harmless and possibly helpful, there are others that can pose a serious health risk or interact with anti-rejection medications.

Abnormalities in liver function tests have been reported after use of certain herbal preparations, and there have been a number of rejection episodes reported in liver transplant patients using St John's Wort, which people take for depression. These herbal preparations may interact with the absorption or metabolism of your anti-rejection drugs, making them less effective in the long run.

In general, it is best to avoid herbal remedies unless you have specific clearance from your transplant doctor.

This information is intended for educational purposes only. Transplant Australia acknowledges that each patient experience is different and does not provide this information as a substitute for medical advice. Please contact your transplant unit or doctor if you need medical advice.

transplant australia

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 63 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.

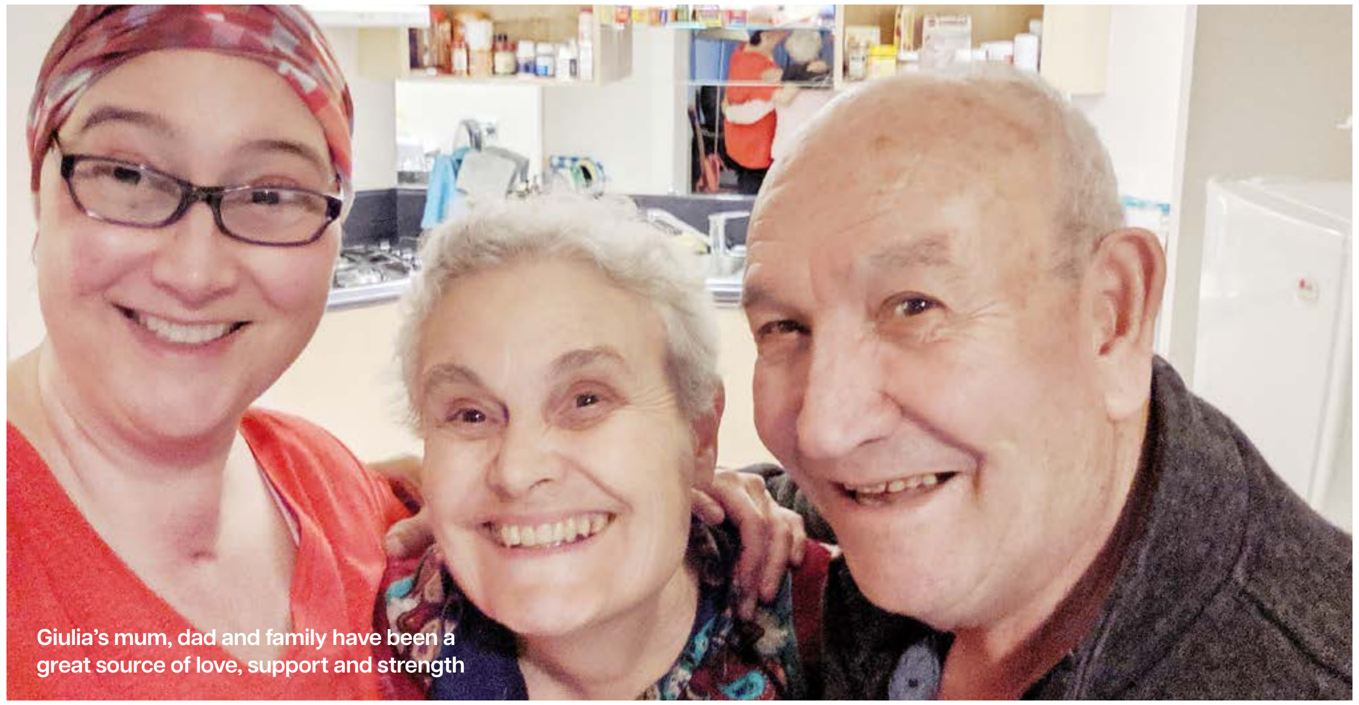
The program is administered on a day-to-day basis by **The Alfred Patient & Family Services Department** (social workers).

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

I live a happy and purposeful life

Transplant can be a challenging journey, but the love and support you receive makes you strong.

By Giulia Papa | *Double lung transplant 21 May, 2019*



Giulia's mum, dad and family have been a great source of love, support and strength

At the age of 33 in 2002, I was living in Adelaide with my family and working as a renal trained registered nurse, when I started to notice extreme fatigue, chest tightness and shortness of breath.

I saw the doctor many times and had tests which showed nothing specific until finally 18 months later after passing out at work I was sent to a cardiologist and diagnosed with Ideopathic Pulmonary Hypertension (IPH).

In 2004 I started treatment for IPH and lasted 13 years before needing to take the path of transplantation.

In 2017 I began to lose my voice due to my grossly enlarged pulmonary artery stretching the floating laryngeal nerve, so the cardiologist referred me to Adelaide's Lung Transplant specialist, who then referred me to The Alfred Lung Transplant team in Melbourne.

In those 13 years, I had to stop nursing due to the whole passing out easily scenario, so I studied Chinese and Japanese acupuncture and was treating a small group of clients when I finally made it onto the transplant list in 2018. I got the call 14 months later and had a double lung transplant in 2019.

I had a long and complicated stay at The Alfred, being in hospital for two and a half months, then a further two and half months in Melbourne doing rehab.

My beautiful mum and dad were with me the whole time, and my sister and brothers and other family and friends came to Melbourne to visit and keep the folks and myself sane which was so amazing for us.

My transplant journey has been up and down the last four years as it has been for many other recipients. My left leg was permanently damaged from complications with ecmo which makes walking painful and slow and my right diaphragm remains paralysed but I have two working legs and enough lung function to live a happy and purposeful life.

I treat clients with Japanese needle therapy and am a qualified Havening Practitioner so I can now help people to recover from trauma and PTSD.

Much love, gratitude and blessings for all the love, support and blessings I received throughout this journey from family and friends, for the amazing staff at The Alfred, and most importantly, to the donor and thoughtful, generous family for this gift of life.

A life of service to others

Looking out for others was what John Griffiths knew and loved. He was wired that way, even in passing.

At the age of nine, Phoebe Griffiths found a nest of baby birds that had fallen from a tree. It came as no surprise that her dad, John, suggested they both take care of them. A former nurse, and then paramedic, caring for others (including wildlife) was in John's DNA.

Over the next little while, together they learned how to raise six baby Rosella's to adulthood, before they were released back into the wild.

Phoebe's memories of her dad are peppered with stories like this one. Looking out for others was what he knew and loved, she says. He was just wired that way.

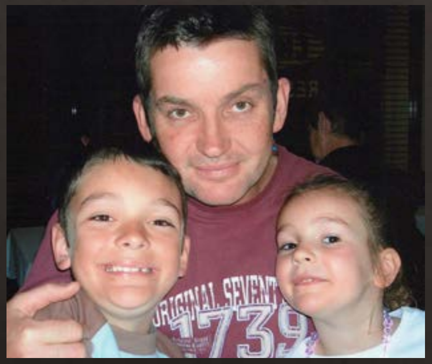
"He was genuinely always there for us as kids, and for the people around him," says Phoebe. "You could ask anyone that we were friends with, if you had to pick the best dad you knew, you would pick him," she says.

Phoebe remembers her dad wore many hats.

"As a paramedic, he would come into school and do talks for us, and we thought it was so cool," says Phoebe.

"He was the coach of our soccer team and basketball team. He even did some work as a counsellor during the rural Victorian droughts," she recalls. "He really did give his life to helping people."

Sadly, in 2019, John fell and struck his head. He was flown to a trauma hospital in Melbourne where it was discovered he had suffered a catastrophic brain haemorrhage.



John with Ethan and Phoebe

As the heartbreaking news was delivered to Phoebe, then 16, and her brother Ethan, then 19, the siblings discovered as their father's next of kin they needed to make an important decision – one, Phoebe says, she never thought she would have to make.

"We got there, and we knew he wasn't going to survive. In the state that I was in, when you don't really think straight, I was thinking 'I just want this over and done with. We won't be able to donate his organs'," she says.

"But I can say I'm lucky the rest of my family were on board and were aware of his wishes," Phoebe says.

With the support of close family members, together Phoebe and her brother learned their father was a registered organ and tissue donor and honoured their father's wishes.

Phoebe says up until then, she had never thought about organ donation, especially not as a 16-year-old. However, knowing her father's dedication to helping others made her decision a little easier.

"It really did open my eyes", she says. "That's why I'm so passionate about raising awareness about the subject now," says Phoebe.

"It's such a hard time, but his job was saving people's lives, and in his last actions he was able to help other people."

"Through all of our grief, there was good that could come out of it, and because of that, it meant other people wouldn't have to go through more grief."

"I feel like that final act of donating his organs is such a testament to what he did in his life. I look back now and think 'wow, I'm so, so glad that we did that.' It's what he would have wanted."

Could you donate 1 minute to give someone a lifetime?

Register at donatelife.gov.au or with 3 taps in your Medicare App

Fast facts

- There are currently around 1,800 Australians on the organ waitlist and 13,000 more on dialysis for kidney failure.
- We know 80% of Australians aged 16+ support organ and tissue donation – yet only 7 million are registered. The number should be closer to 16 million.
- When it comes to those aged 16-24, only around 1 in 10 are registered.
- Don't forget to tell your family you want to be a donor - someone's life may depend on it.
- Your family will always be asked to support your decision before organ donation goes ahead. They are much more likely to agree if they know you want to be a donor.
- One organ donor can save the lives of up to 7 people and change the lives of many more through eye and tissue donation.

Article courtesy DonateLife Victoria

After her heart transplant Vanessa is enjoying every single minute of her second chance at life, especially with her nephew and niece.

Half a heart can only get you so far

Vanessa Gale's recent heart transplant was the culmination of a lifelong battle for survival.

By Graeme Klemm and Vanessa Gale | *Heart transplant 23 January 2022*

All Vanessa's family in December 2022, her first Christmas with her new heart celebrating DonateLife.

When you look closely, the human body is remarkably adaptable. Vanessa Gale, a school teacher from Strathalbyn in South Australia can testify to this very well.

Mother nature can be brutal sometimes and Vanessa was born with only half a functioning heart as a direct result of a rare congenital heart condition called 'hypoplastic left heart syndrome' which meant that the left side of her heart was unable to effectively pump blood around her body.

This condition resulted in the need for Vanessa to undergo open heart surgery twice, once as a newborn and then again as a seven year old.

The fact that she was able to live successfully for over three decades from that surgery illustrates how her body had sufficiently adapted to her diminished cardiac capability.

The challenges of not having a fully functioning heart, however, meant that Vanessa's childhood, teens and early adulthood was a period where she had little stamina, felt nauseous most of the time and was constantly worried about whether she was going to survive.

"Growing up my life was always tiring. I was always puffed and a blue/purple colour from a lack of oxygen."

"I could never run or walk up hills. I could never play sports or keep up with my friends. I would always be so cold and need plenty of layers on to keep warm. I stayed inside a lot."

"When I was younger after surgeries and hospital stays I did some schooling in the hospital, but I was always puffed and breathless."

"Unfortunately due to everything that I was experiencing it meant that I often came down with colds and viruses."

It eventually came to the point where Vanessa was living a roller coaster of hospital admissions, especially the last two or three years prior to her transplant.

"I was having really, really bad heart palpitations. I even went into cardiac arrest at one stage in my loungeroom at home," she said.

"There were blood clots in my heart, my liver wasn't working very well as I contracted cardiac liver cirrhosis because of my condition and I even had to have oxygen at home.

My doctor told me I was in severe heart failure which was pretty hard to hear. He said that the 'Fontan' operation that I had when I was seven wasn't working anymore."

" I couldn't even put out my own bin it was that bad."

"During my life, I can vividly remember being transferred to hospital in Adelaide a number of times by ambulance, even in a helicopter once."

The reality of her condition finally hit home when Vanessa was given advice that she would require a heart transplant in order to sustain her life into the future. It was sobering news, but something she embraced with all of her own energy as well as the support of a large and loving family.

Like many people that find themselves on the transplant pathway, life itself had been a journey for Vanessa, and this was just another challenge to meet head on.

It was after the cardiac arrest in her loungeroom that it became clear Vanessa had to step away from her dream job as a teacher at Eastern Fleurieu School R-6 campus in Strathalbyn as she was just too unwell to perform her role. She was advised by her cardiologist to stay home as her oxygen levels were in the 60's by then.

Dr Patrick Disney, Vanessa's long term cardiologist in Adelaide, was the first to identify that she would need a heart transplant. However, it was a long way between regional Strathalbyn and the two major heart transplant centres in Australia – The Alfred in Melbourne and St Vincent's in Sydney.


The moment Vanessa's transplant listing at The Alfred became real.


Vanessa has found a community gym in Strathalbyn to continue her rehabilitation.

Negotiating the reality of living in a regional setting meant that Vanessa's transplant work-up involved spending time as an inpatient at the Royal Adelaide Hospital under the watchful eye of Cardiologist Doctor Michael Stokes and his team.

Vanessa was sent to The Alfred as the hospital for her transplant which had some good synergy as that is where Dr Stokes had trained and was in regular contact with the key cardiologists and surgeons.

As it turned out, Vanessa's work-up involved months of medical testing and psychological assessment in order to list her for transplant.

"I was very sick as they were doing all the work-up. There were so many tests and interviews I couldn't believe it," Vanessa recalled.

"Right near the end of the work-up I flew to The Alfred to meet the transplant team, have some last minute tests and sign all the paperwork."

Being on the transplant list carries significant emotional weight and responsibility.

"I had to carry my phone around with me everywhere in case it rang with a call from The Alfred with news about my new heart," said Vanessa in our recent chat.

The wait for 'the call' is a time of great anticipation for many patients, while others find themselves becoming quite nervous about what lays ahead.

There were many factors that had to be taken into account to ensure that a viable heart for Vanessa would ultimately match her needs and lead to a successful outcome including body size, blood, tissue and antibody compatibility. Once all these factors, and more, aligned in Vanessa's favour, The Alfred would call her for the life-saving transplant surgery.

The seemingly random nature of when a viable heart becomes available means 'the call' can come at any time after a patient is listed.

In Vanessa's case, it was just 16 days.

"I was not expecting to get a call so soon. That was totally unexpected, but it made me so excited to be able to get well with a new heart" she recalled.

As of today, some 18 months after her transplant, Vanessa continues to work hard to ensure her new heart has the best chance of success.

"I've been told many times by the doctors and cardiologists that treated me that a heart transplant is probably the biggest operation and most amount of trauma one's body can go through," Vanessa said.

It hasn't been easy being immunosuppressed, with so many biopsies to keep assessing whether her new heart is showing any signs of rejection, battling a bout of COVID and catching colds that have really knocked her around.

Thanks to Vanessa's care for herself and attention to detail with her medications, the one constant in the last 18 months has been that her new heart has been beating strongly and is in great condition. She is very grateful to God for this.

Her prospects for a much longer life are looking significantly positive since her transplant – something that she had only dreamed of.

Many transplant patients, regardless of the organ, have spoken of the significant financial and social impact that their illness has had on both them and often their immediate family.

Vanessa's family created a GoFundMe page to support her financially as she had been unable to work for a period of time leading into her transplant. The donations assisted with a variety of things including accommodation, taxis, food, travel expenses and even an iWatch with its built in heart monitoring technology to aid in her recovery and rehabilitation.


Vanessa had been teaching at Eastern Fleurieu School R- 6 campus in Strathalbyn when she got the news that she required a heart transplant – and the staff and students at this wonderful regional school welcomed her back enthusiastically for a visit recently when she arrived back home from her transplant.

Strathalbyn is a tight-knit regional community and Vanessa has had incredible support from all corners of the town and surrounding area.

It's little surprise, towns like this get behind their people in need, especially when they have grown up with them. Vanessa is a third-generation local.

"It was just incredible, the support of the whole community. There's no way I could have done the transplant without the GoFundMe; it's just mind blowing", she said.

The community raised a remarkable $22,635 to support Vanessa.

"People were sending me letters of support, presents, texting me every day and praying for me. It has been unbelievable, the whole town and my Church were loving and caring for me the whole time."

"And it didn't stop there, they supported my family as well, checking in with them, cooking meals, gardening and even feeding my cat for me. Incredible."

Vanessa has received so much more than just a new heart and she is very appreciative and mindful of the precious nature of organ donation. The photo on page 35 testifies to her, and her family's support of DonateLife who recently celebrated DonateLife Week to raise awareness, promote and encourage organ donation in Australia.

"I can't put into words the gratitude I feel for my donor's family for giving me the chance of a longer, better life. I am so thankful to them."

"And what can I say about my family and friends other than I love you so much and want you to know it will be my turn one day and I will be there for you."

I would encourage anyone who has had a transplant to compete at the Australian Games next year.

Jade Mitchell (left) with Emmy O'Neill before the Opening Parade at Perth's World Transplant Games earlier this year

TX Active and looking pretty good

Gearing up the Australian team's World Transplant Games parade uniform is a dream come true!

Jade Mitchell, Director TX Active | *Double lung transplant 17 July, 2018*

My business TX Active was conceptualised whilst I was attending the transplant rehab gym between 2018 and 2019. I wanted to give back to the transplant community in a practical way that motivated and prepared people for an active life post transplant by gifting activewear.

For every few items purchased on our website we gift the same items to organ transplant recipients. The business is making small progress and I am really trying to engage with the community to help celebrate our achievements.

Once I launched TX Active I contacted Transplant Australia to introduce myself and find out what they did. I had heard about the Transplant Games and I thought if rehab gym is the beginning of a new active life after transplant then perhaps the peak would be competing at the Transplant Games.

I wanted to know more about what that involved and let Transplant Australia know about my idea to gift TX Active to organ transplant recipients.

Six months down the road Transplant Australia contacted me to ask if I would be interested in helping design and manufacture the Australian team parade uniforms for the World Transplant Games. The team is a tight knit community and they felt it was a fantastic story that the uniforms were provided by a transplant recipient.

The Games were hosted in Perth WA in April 2023. I was thrilled that Transplant Australia had considered an organ transplant recipient to be involved and it was an amazing experience and honour.

Jade with Ken Farmer

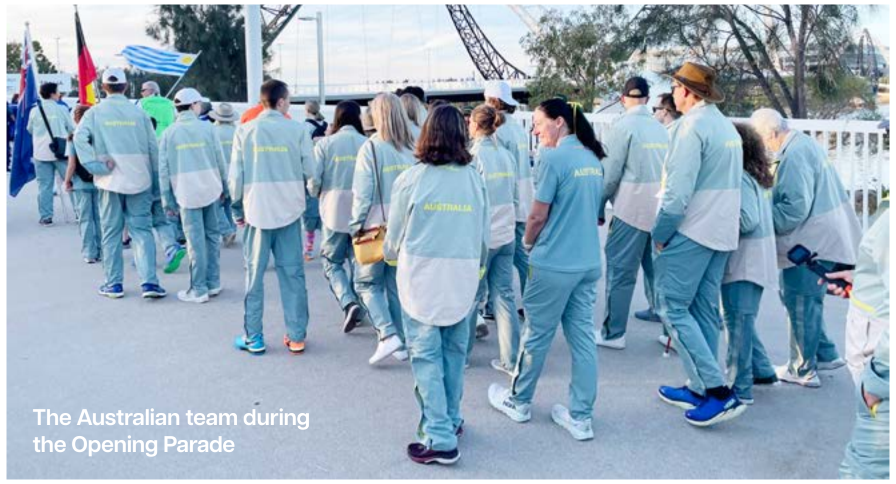
The parade uniform design was inspired by the Australian bush. Green and cream from a variety of gum trees and the bright yellow of our native wattle. I also wanted to connect the uniforms to our First Nations People. I was introduced to Ken Famer and his Indigenous artwork through Transplant Australia. Ken is a fellow transplant recipient.

I felt like it would be an incomplete experience if I didn't compete at the games so I contacted a personal trainer friend and got a training plan to prepare me to compete in swimming at the World Transplant Games.

The World Games is an experience I would highly recommend. It was my first ever games. The Australian Team were all amazing people. Connections you make with team mates are wonderful and instant. Meeting people from all over the world who have had transplants and are showcasing their passion for life and sport was so uplifting. The positive energy was truely inspiring.

Training after transplant still has its issues. Muscles recover differently and niggly things pop up as a result of medications which still need managing. It's not straight forward but I would encourage anyone who has had a transplant to compete at the Australian Games next year.

Don't be afraid you may not be good enough because there are all abilities and everyone is there having a great time and giving it their best. It's more than a competition, it really feels great to be involved.



The Australian team during the Opening Parade

Connecting is in our DNA

Our social events are getting back into a rhythm now and are vital to our transplant family feeling supported.

Christmas BBQ 2022... So special!

It was such a long time since we had been able to catch up with our transplant friends to see how they are going. We kept looking forward to inviting all those new patients and their families to join us.

A new COVID wave was beginning as our AGM and Committee Meeting were held on 8 November. What do we do about the 2022 Christmas BBQ? It was short notice if we were to go ahead on the traditional last Sunday in November.

So on that night the decision was made. Yes we wanted a BBQ!

Tessa, newly appointed President (and someone who hadn't had the opportunity to attend a BBQ), offered to immediately set in motion what was required to obtain the permit for the use of Fawkner Park.

Martina offered to collect the BBQ with the help of family and their friends and be responsible for everything on the day. In Adelaide Graeme got to work on a flyer and Martina sent out the invitations and took notices to display at The Alfred.

Wanda was working in the background organising the raffle. With only a weeks notice who would come? But come they did – old and new faces with their families and friends including those who came along to honour those who were no longer with us. It was very much appreciated.

We know Maarit would be proud that the BBQ did happen. As Secretary she had been trying to organise social events and was positive that one day we would do it!

Thanks to everyone that contributed to such a fabulous day. Santa seemed to be enjoying himself too.

The HLTTV 2023 Christmas BBQ will take place on Sunday 26 November at Fawkner Park, 11.30am to 2.30pm.

Easter BBQ 2023

Those who came along to the Easter BBQ found loads of Easter eggs to choose as prizes as well as lots of other interesting items. While usually a smaller turnout for the Easter BBQ it is always enjoyable and gives everyone another chance to catch up.

It was a perfect day for that time of year. Thanks again to Martina and her family and to others who helped out including the sparkling Easter Bunny. Sam captured the day on video.

Both events are an opportunity for catching up and fundraising. We look forward to seeing you at the next opportunity to connect with your transplant family at our 2023 Christmas BBQ in Fawkner Park.

< Lung recipient Alex Dassanaike and his wife Sulan

< Alex and heart recipient Gaylynn Pinniger

Exhibiting passion and gratitude

What better way to define Alex's second chance at life than dedicating his artwork to his donor, his hero.

I was talking to a friend on the telephone when she mentioned she was coming to Melbourne for her friend's Art Show & Fundraiser. She happened to mention that he had a lung transplant. My ears pricked up. He must be an Alfred transplant patient like me. I have to meet him!

I met Alex at his 2020 Art Show on Sunday April 24 and thoroughly enjoyed the day. Alex and I are around the same age. Alex had his lung transplant just two years ago and I had my heart transplant almost 20 years ago. His journey was very different because of COVID restrictions. Alex filled in much of his time painting.

Alex's wife Sulan asked him what he was going to do with all his artwork.

With the support of Lungitude, holding an Art Show to raise money for lung transplant research was one way they could give back. A team effort by family and friends contributed to a very successful Art Show. The paintings were reasonably priced and all proceeds were donated - raising over $5,000 for Lungitude.

By Gaylynn Pinniger
Heart transplant 23 Dec, 2002

This photo (above) portrays the universal closeness of organ recipients.

Both Gaylynn and myself pay our gratitude for the extra life we have been granted by our Donors. We thank our Donor Families for their act of generosity made during a time of great personal loss. There are four of us here in this photo, a lung and a heart of two angels making up the other two.

May their souls rest in peace.
Alex Asoka Dassanaike

About the artist

My name is Alex Asoka Dassanaike. I was born in Sri Lanka in 1949. I moved to Australia with my family in 1987.

In 2015 I was diagnosed with a terminal lung condition. Over the following years my health deteriorated, as did my quality of life.

In 2018, requiring oxygen 24 hours per day and hardly able to do anything, I was placed on the lung transplant waiting list. I was one of the oldest people to be put on the list, but given my healthy condition and lifestyle, apart from the lungs, the doctors at The Alfred thought it was worth a try.

In February 2020 I received a new lung, and a new life. Recovery was hard, but the staff and care at the Alfred Hospital were amazing. With my new lung I am able to once again enjoy my family and friends, as well as to renew my passion for my art and my gardening.

I dedicated my Art Exhibition to my Donor, my Hero.

Top tips for transplant travel

If your goal post transplant is to travel, you need to consider a variety of issues to ensure a safe, enjoyable trip.

DOCUMENTS TO TRAVEL WITH

Whether you're travelling in Australia or overseas, carrying a letter from your transplant clinic with your medications, dosages, main diagnoses and details of Alfred contacts is a good idea. The letter can help if you get sick and need to access care away from your usual providers, and will also help you get through customs if you're carrying medications when travelling overseas. Make sure you leave pharmacy labels on medication bottles and packages as well to make it easier to get through customs if you are stopped.

RECIPROCAL HEALTH CARE AGREEMENTS

Some countries – including NZ and the UK – have reciprocal health care agreements with Australia. That means that if you get acutely unwell and can't travel home, you can get help with the cost of essential medical treatment. Reciprocal health agreements don't replace the need for travel insurance, but may make access to health services easier where the agreements exist.

TALK TO YOUR DOCTORS

Before you set anything in stone, have a chat to your transplant team about your particular needs, what you should consider, and whether some travel ideas might be off the table at the moment.

TRAVEL CLINIC

Did you know that The Alfred has a travel clinic? It is bulk billed, operates outside working hours, and are familiar with the ins and outs of travelling with transplant! Just ask your transplant doctor for a referral before you head overseas.

CHECK RESTRICTIONS ON CARRYING MEDICATIONS OR LIQUIDS BEFORE YOU GO

The government Smart Traveller website **www.smarttraveller.gov.au** is invaluable for overseas travel. Other countries have different rules about bringing in medications – particularly pain medications – that you need to check and understand before you travel. It's also important you understand what can be taken on planes (liquids, syringes etc) and seek exemptions where these items are restricted if you need them while you're in the air.

TRAVEL INSURANCE

If you're headed overseas, it's sensible to travel with insurance that covers your transplant. This can increase the costs of your trip significantly, and can be difficult to get for some countries, or if you are particularly unwell, so be sure to factor the time and costs associated with getting insurance into your planning. The companies that will insure transplant recipients changes from time to time, but at HLTTV we tend to have a few travellers among our members and keep our ear to the ground about what's available. Contact us via **patientsupport@hlttv.org.au** or via social media if you want to discuss our recent experience with travel insurance companies. Transplant Australia are also a great source of travel insurance information and advice: **www.transplant.org.au**

What are your top travel tips?

Head to our Facebook page and let us know or send us an email at klemms@adam.com.au to share them with the HLTTV community.

Exactly what the name suggests

A respite house for use by pre and post heart and/or lung transplant patients and their carers.

The Heart to Heart Respite House in Barmah is exactly what the name suggests: a respite house for use by pre and post heart and/or lung transplant patients and their carers, so that they may have a place to rest, recuperate and recover.

The house became the property of the Rotary Club of Nathalia in 2013, at the request of the late Bill Vickers (whose "baby" this property was, and which opened in 2009), and it is an honour to be custodians and caretakers of such a place.

Barmah is a small Murray River town, about 239 kms north of Melbourne and 36 km north-east of Echuca. Barmah is best known as the gateway to the superb Barmah State Forest which contains the largest redgum forest in the world.

Barmah has a post office, general store, fuel, and the Barmah Hotel which serves delicious, well priced meals, and there are even seniors' meals on the menu.

There is plenty to see and do in the area: the paddle steamers and historic wharf at Echuca (as well as shops, hotels, cinema, etc.); a forest drive into the Barmah forest is two-wheel drive friendly and there are plenty of bushwalking tracks (emus, kangaroos and even brumbies may be spotted);

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

For bookings
and information:
Martina McArdle
Ph 0409 957 492
martina@hlttv.org.au

HEART TO HEART RESPITE HOUSE

Nathalia is a small town, about 25 kms towards Melbourne, and has a few shops, bakery, cafes and a visitor information centre.

In the opposite direction, towards Yarrawonga, are a few towns, one of which...Strathmerton... has "Cactus Country" and it is well worth visiting. Some of the not too distant NSW towns are Moama, Tocumwal, Deniliquin, should one wish to go interstate.

The respite house itself is all electric and set up with all that people may need.

There are two bedrooms (1 Queen, 1 Twin), with a TV in each; the bathroom has disabled facilities; there is a laundry with washing machine; and the kitchen is fully equipped.

The lounge is spacious with plenty of seating and there is a TV, stereo, DVD's and CD's, with a selection of books and magazines.

The dining table seats six. Heating and cooling is done with a very effective reverse cycle unit.

Outdoors there is a carport, washing line, a verandah all around the house (with disability access ramp), an outdoor table and chairs as well as an electric BBQ.

Guests are charged $15 per night and there is also a linen hire charge of $5 per stay (not per night), or people can, of course, bring their own. Of course the house is run as not for profit (thus the low rates), always has and will, and we need to ask guests for payment because there are bills to pay.

Now for the bad news, which is that the house is not being used enough... and the bills don't stop!

Covid hurt us, as it did thousands of people and businesses; we also had floods in the area in October that caused cancellations. This year only February and March had totals of 11 and 14 nights' stays respectively (bookings are usually for up to 6 nights but people stay anywhere between 1 and 10 nights), April was down to 8, May had 2, January and June 0, and July 2 also.

There are no bookings in the foreseeable future I'm sorry to say so we need your help.

PLEASE COME and spend a bit of time in this beautiful part of Victoria (almost New South Wales)... you will not regret it. The visitors' book is full of praise and we are very proud.

The H2H committee has talked about the future of the Heart to Heart Respite House and it looks bleak if the people it was built for don't support it by spending time there.

We cannot keep outlaying money for the upkeep and maintenance of the place indefinitely, with nothing coming in to help pay the expenses. So it is up to YOU. Please support this very worthwhile respite house and help keep Bill Vickers' legacy alive.

Thank you.

Eve Attwood
Treasurer, Heart to Heart Respite House Inc. and Rotary member

Please visit the H2H Facebook page... *Heart to Heart Respite House Inc* for more information. Past visitors are very welcome to leave comments there.

Martina McArdle, HLTTV committee member, with Rani from Rosco's @ Chevron promoting Donate Life.

Russco's put Donate Life stickers on their coffee cups to promote patrons to scan a QR code and register to become a donor.

The promotional poster that Martina is holding features another HLTTV committee member, Petra Brosch who was involved in the Donate Life Week campaign in 2021.

A mother's truly exceptional love

Most parents dream of a happy, healthy, long life for their children but when you confront the alternative the bond can become even stronger.

By Michelle Richter | *Mother to Kurt, BiVADs 21 July 2017*

I met Michelle Richter and her son Kurt just over six years ago when I was in the Alfred undergoing my own LVAD implantation and recovery. She was a typical mum who clearly loved her son, but when I eventually heard the full story about Kurt, I came to appreciate the depth of that bond between them. In this article she describes her experience of being a mother and carer. Editor

Kurt with his mum, Michelle, and sisters Katelyn (left) and Stephanie (right)

Hi, my name is Michelle and I am a mother to a gorgeous son and two beautiful daughters. I believed my life would be perfect when I married my soulmate after turning 19. I have so many happy memories of course which we continue to make so this is just part of my story.

Kurt suffered from Heart Failure after completing 12 months of aggressive Chemotherapy at Peter MacCallum Cancer Centre for a very rare and aggressive form of Bone Cancer (Chondroblastic Osteosarcoma). He was diagnosed with cancer at the age of 16 and had to leave school for treatment.

I am also a widow after losing my husband and father to my three children to Leukaemia in 2009.

As you can imagine, to find out my son had cancer was almost too much to bare, but I was by his side every day and slept by his hospital bed every night.

He was frightened for his life, especially after losing his Dad, so I had to be his rock, and as he calls me, his best mate. As long as he was OK then I was OK.

Spending time with him was my happy place.

My relief that he was assessed to be in remission on 13th of April 2017 turned to absolute devastation for him some 12 weeks later when we found that Kurt was suffering from heart failure due to the MAP chemotherapy.

We were immediately transferred to the Alfred Hospital and after having a right heart Cath, the news was heartbreaking. Kurt only had 10% of normal heart function and would, within the next two days, undergo open heart surgery to receive not only an LVAD but also an RVAD. He was 17.

The Alfred was the same hospital where my husband was treated for two years only to pass away there which weighed heavily on Kurt.

Kurt was very unwell and it almost killed me to watch him go through yet another horrific journey.

The first open heart surgery to insert the BiVADS was 20 July 17. Unfortunately, overnight he had severe internal bleeding from the heart.

The second open heart surgery was 21 July, but he experienced a blood clot in his right ventricle which got stuck in the RVAD and it stopped working!

The third open heart surgery to completely replace the RVAD was performed on 24 July. I sat by his bedside in ICU from 7am until 11pm every day for weeks and continued to do so during the following three months on Ward 3E.

Kurt wanted me there before he woke in the morning and after he went to sleep in the evening. He was so distressed and anxious, in an enormous amount of pain.

Alarmingly, as a boy of just over 6 feet in height, he had dropped to a weight of just 46 kilos.

The Cardiologists admitted to me later that year that they thought he would pass on several occasions as he was so unwell.

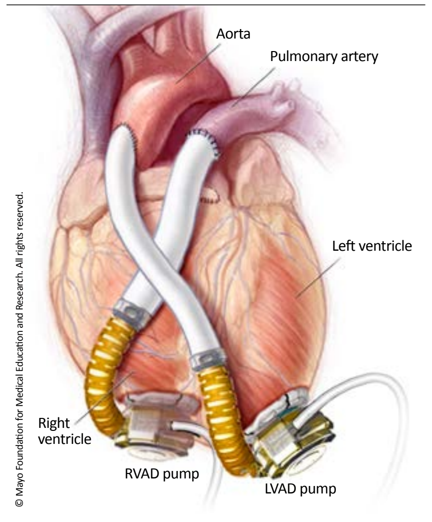
My world seemed completely shattered but Kurt kept me going with his immense strength and determination.

During those five months I stayed at a hotel on St Kilda road and on several occasions received emergency phone calls in the middle of the night and would run as fast as my feet would take me just to be by his side.

Finally, after regaining strength and undergoing regular rehabilitation with the physiotherapists, Kurt was able to come home with me.

Although he had his older sisters there with him, being at home was difficult for him too. He had a traumatic first year and was feeling like he couldn't take any more as his 18th Birthday approached.

Kurt didn't want to see anyone and just felt broken. I felt broken too, questioning just how much was my son supposed to endure and at what cost?



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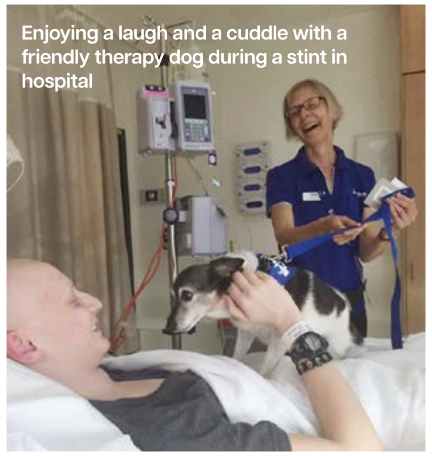
The VAD girls call him their VAD poster boy... he really is a true inspiration.



Enjoying a laugh and a cuddle with a friendly therapy dog during a stint in hospital

So I organised a dinner with nine of his best friends from primary school, a very close knit group that supported Kurt as much as he would allow.

He was angry with me for organising them to come and didn't want to see them but as it turned out, a miracle happened when the first couple of girls turned up and then slowly the others. He was smiling from ear to ear. I don't think he realised how much he had missed them and how dearly they wanted to see him.

That was a huge turning point for Kurt as he accepted his new way of life, living on life support and quickly learning how to adapt.

I burst into tears one day when he came downstairs and told me he had enrolled himself in a course at Swinburne University. I was so proud of him. He is currently doing his second year of a Business Degree.

As a mother I'm thankful that I can stay at home and be there for Kurt. As someone who is finding his confidence again, he insists on catching the train and going to Uni to regain his independence and meet new friends.

Before lockdown, I would drive him and pick him up from the train and help him in any way I could, dressings, medication, hospital clinic etc.

He was a new young man, even getting to the point where he told us he didn't want a heart transplant as he was so used to his BiVADS and everything that went along with them.

He learned to paint by going to art classes held at the Peter MacCallum Cancer Centre in the city. He has always been an avid gamer and loves to play his guitar.

It has been of great benefit that Kurt has wanted to talk to counsellors since being diagnosed with cancer and we are both blessed with loving friends for support.

I decided it was important for Kurt to meet someone closer to his age that was a transplant recipient. They met and talked in depth about the process of transitioning from VAD to heart transplant.

Six months ago he announced that he was ready to go on the transplant list. Unfortunately, COVID-19 had hit and they weren't doing any work-ups at that time.

Unfortunately in early September Kurt was feeling unwell and had to spend a week at the Alfred. They found that the tube from the RVAD to his aorta had a kink in it, (like a garden hose), dangerously slowing the flow of blood and as a result he was put on the Emergency Heart Transplant list.

We are waiting for THE CALL at any minute. Kurt is excited to start a new chapter of his life but of course anxious about what lies ahead.

COVID-19 protocols at the Alfred won't allow me to be at the hospital with him for the entirety of his stay which will be difficult. I will look forward to the first time Kurt FaceTimes me. I found myself crying recently as I cooked dinner one night just thinking about my son going through this alone and the terrible memories I have of seeing my husband go through similar circumstances. I'm afraid of losing my son, but I know one thing is for sure, he is at the very best hospital, being taken care of by the wonderful doctors and nurses who he knows so well.

Kurt exhibiting some of his paintings

He is strong, brave and resilient and I hope and pray for a full recovery after transplant. The VAD girls call him their VAD poster boy. He's strong, fit and now weighs 80kg and looks great. He really is a true inspiration.

He looks forward to going to a party in the future and driving a car and all the things he's missed out on for so long.

As they say – new heart… new start!

I can't wait for him to start his new life! I'm so very proud to call him my son and I really am so blessed that he has the strong spirit that he's maintained throughout this whole life shattering ordeal.

God bless all the donors and recipients.

VALE

My best friend

Jason Kurniawan's euology spoken by him at Kurt's funeral

I'm Jason – Kurt's lifelong best friend. We went to primary school together, we gamed together, we went bike riding together and we played a lot of boardgames together – I always beat him.

Kurt and I used to have many conversations. Some were silly – most of them were silly actually – but sometimes we would have these deep conversations about our personal challenges in our lives. I always saw Kurt as someone who had mastered his mind, and I would always ask him for advice about how to deal with my own challenges.

One day after one of these conversations we had, I saw him, and he had bought me this book. It's the Emperor's Handbook and it's a collection of quotes from a former Roman Emperor Marcus Aurelius – we all know Kurt loved his history.

One of the quotes in this book was that "The Happiness of your life depends on the quality of your thoughts". This is a quote that summarises Kurt – he was a guy who was always positive throughout his entire life.

While his Dad was suffering from Leukaemia he shaved his head in front of the whole school, we were in Year 3 at the time – imagine the courage that takes.

He battled cancer and won. Thrived on his life supporting Bi Vads for six years.

And even after this adversity he went to study at University to get his Bachelor of Business at Swinburne.

Kurt was able to get around on his Trek e-bike. He never knew this but I was always more scared for him than he was for himself. He learnt how to drive recently and bought himself his dream car – a Suzuki Jimny.

Jason Kurniawan with Kurt

One of the best things that happened to him over the last year was that he met his beautiful girlfriend Bel. I say this because we spent many times together going out for Korean BBQ and listening to live performances at the jazz club – two of Kurt's favourite things.

Many people say Bel is the female version of Kurt and my heart goes out to her in this tough time.

Kurt… we will miss spending time with you and doing these things that you loved most – but we will never forget the eternally positive impact that you have made on everyone's life, and especially ours.

I believe there are moments in everyone's life when they put everything aside and realise that it's important to look outside themselves and take the responsibility of supporting others.

Earlier this year my wife, Andrea and I flew to Melbourne with another couple to give our deepest respect to a young man and his family in one of those moments.

The article by Michelle Richter about her son Kurt on these last few pages featured in a previous edition of The Circulator (2020), but I wanted to honour an incredible young man whose transplant journey was sadly and tragically cut short by including it again in this edition.

It was truly inspiring and symbolic of Kurt's love, humanity and connection to witness the number of people who came from every corner of Melbourne, Victoria and interstate to pay their respects.

From left: Heart transplant recipients Bruce, Graeme, Rod, Glen and Jason remember Kurt

Family, friends, school mates and members of the transplant community shed tears and told stories about someone who had touched them with courage, humour, selflessness and determination. Editor

What comfort zone?

Double lung transplant recipient Sam Ira is on a mission to connect with other recipients to live their best lives


Martina | Dbl Lungs - 11 September 2009


Petra | Heart - 9 July, 2018


Sam | Dbl Lungs - 15 August 2009 and 23 April 2013


Thor | Dbl Lungs - 1 December, 2017

Heart transplant recipient Petra Brosch (pictured), a HLTTV committee member, organised a great fundraiser to benefit the Heart & Lung Trust of Victoria. With a handful of brave fellow transplant recipients, the group raised $2541 for the Trust by taking a big leap of faith and skydiving from 15,000 feet.

Sam is 44 years old and due to Cystic Fibrosis he has had double lung transplants twice – on 15 August 2009, and then re-transplanted on 23 April 2013 as well as a pulmonary artery in 2014. He is a man with unlimited energy and drive to live his best life after transplant, this details some of his adventures.

I still can't believe that after going through all these health issues I've still achieved some amazing goals on my bucket list!

I hadn't travelled for over 15 years due to my health. After I received my first gift of life (1st double lung transplant) I felt amazing and I finally had the opportunity to build two townhouses with my brother who also has CF. I still couldn't believe that all this was happening and I was feeling like a completely new person. I was able to walk, run, no oxygen and no physio requirements.

Actually, I still can't believe it!

I firstly went to Tasmania in September 2018 with a good friend, then a week later I travelled to the Gold Coast for The Australian Transplant Games and won gold and silver medals for Ten Pin bowling (singles and doubles respectively).

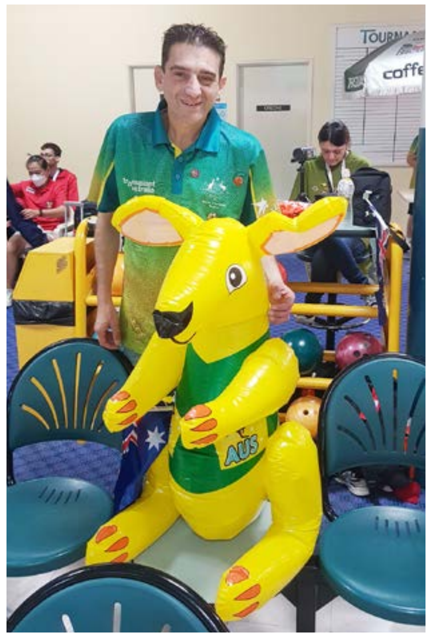
I even booked a trip to Mauritius for a good friend's wedding to celebrate with them as well as film it as I'm a video producer. Unfortunately my trip was postponed as my lung function dropped from 95% to 18%. Although it was disappointing, I had no choice and was back on the list once again for a second double lung transplant. Thankfully I got to take the trip later.

I waited 10 weeks and received my second Gift of life, my second double lung transplant which I still currently have. I celebrated my 10th anniversary in April this year (2023), an incredible milestone in itself.

It has felt like a never ending story that I could write a book about.


The incredible views of Antarctica on my one day flyover

To achieve so many goals and happy memories with my amazing family and friends constantly reminds me of the generosity of my wonderful donors and their families and the exceptional role that Donate Life plays in the Australian transplant community. I couldn't have done any of this without them.



I needed to use Hospital in the Home (HITH) for nearly three years and broke the record as their longest patient ever. I'm still waiting for the Diploma!

After my second double lung transplant I was able to travel to the World Transplant Games in Newcastle/London, as well as spending time in Germany and Italy.

One of my most memorable experiences has been Skydiving for Donate Life week 2021 with other recipients from our transplant community. What an incredible experience.

I feel blessed that through an agreement with a good friend who won a CF Galla Ball raffle for a one day trip to Antarctica I was able to have the experience of a lifetime flying to the south pole. I never even thought it was on my bucket list – go figure.

I have also been to visit Uluru in the Northern Territory. It reminded me of how fortunate I have been – from not being able to walk and even needing regular oxygen to walking kilometres around Ayers Rock on a 40 degree Celsius day. I had come a long, long way.

Recently I have been able to attend Fast Track V8 Race experience driving a V8 Supercar at Sandown Raceway (Melbourne). I could finally speed without the risk of a fine. Exhilarating.

The 2023 World Transplant Games were held in Perth and I was able to win a silver medal for Ten Pin Bowling and a bronze for Darts.

It's such an amazing experience to attend this gathering of transplant recipients.

I urge anyone who has had a transplant to consider attending an event like this to join with others and have fun. It's not about competing or winning, it's just about connecting.

Sam Ira


The exquisite beauty of Ulura and surrounding areas


THE HLTTV WISH TO ACKNOWLEDGE THE PASSING OF MEMBERS OF OUR 'TRANSPLANT' FAMILY DURING THE LAST TWELVE MONTHS.
WE CELEBRATE THEIR LIVES, HONOUR THEIR MEMORIES AND SEND OUR CONDOLENCE TO THEIR FAMILIES AND LOVED ONES.

Every day I wake up it is a blessing.
I was privileged to have this opportunity.

One pillow has never felt so good!

Until you've been through great adversity, you don't realise the simplest pleasures are those you value most.

By Kathie Metcalfe | *Heart transplant 18 April, 2021*

I was eighteen years old when I was diagnosed with a mitral valve prolapse. It was discovered after a fall off a horse.

Unbeknown to me, my heart rate was high. I felt nauseous and unwell. My mother took me to the family doctor who saw my heart rate and urgently referred me to a cardiologist. The cardiologist gave me some medication to slow the heart down, carried out an ultrasound and concluded that this was a minor issue and no medication was needed at this time. The cardiologist asked me to come back in twelve months time. No panic, no stress, everything was fine, not a big deal.

Fast forward a few years with no issues or misadventure, my first child Jack came into the world with no trouble at all.

I was pregnant with my second child, twenty weeks into the pregnancy and I was feeling out of breath, extremely tired and was struggling in general. At the time we were moving house, had a litter of puppies and in the middle of a heat wave. Well, no wonder I felt exhausted.

None the less, a visit to my doctor would be the safe thing to do. The doctor agreed with me and asked me to slow down and keep my fluids up. I followed the doctor's instructions however continued to remain unwell but believed that after the puppies went to their new home and we were in our new home, things would settle.

After the move to Murray Bridge from Two Wells, I was starting to feel worse. Being in a new town I found myself looking for a new GP with a view to making an appointment. The new GP noticed some irregularities in my pulse and heartbeat.

A stroke of luck came to me that day as my Cardiologist was in the same building at the time.

At a moment's notice I was taken to a different area of the medical centre and had an ultrasound with the Cardiologist present. It was that moment where I received terrible news, I had Cardiomyopathy.

In the following days I was put on medication and had many tests performed to diagnose what type of cardiomyopathy. The conclusion was Idiopathic Cardiomyopathy.

The next stage to this news was the care of my unborn child as this was a precarious situation. There was a 50% chance that my child or I may not survive, so complete rest was strongly recommended. I was told that the condition, in conjunction with the medication, would cause the baby to have slow growth and possible underdeveloped organs. Termination of the pregnancy was offered but it never crossed my mind to agree.

I was booked into the hospital a month before birth to ensure a close eye was kept on things. A very well-planned cesarean was carried out and to my delight, everything went to plan. I am pleased to say my eldest son Jack, who has just turned fifteen years old, is a strapping young man, almost 190cms tall with a size fourteen foot and a heart of gold. What a blessing.

As time passed, taking more medication and with the installation of a defibrillator, I was able to carry on with every day activities, such as employment, socialising, breeding German Shepherds, caring for my children, performing household duties and regular checkups with my cardiologist. My condition was managed and life went on as usual.

A few years down the track, my health took another turn for the worse. I was not able to sleep laying flat, feeling out of breath and ill. Again, I made an appointment with my GP and unfortunately, I was diagnosed to be in heart failure.

My GP told to me to go home, pack a bag and present myself to the Royal Adelaide Hospital. My GP sent a letter to the hospital of my impending visit. After a week in hospital and a change of medication, things got back on track. My EF got back up to 35, I was able to manage once more.

However this was short lived and my health continued to decline. My specialist was now discussing a possible heart transplant. I had a few tests done – stress test, MRI scans etc – but with the outcome of these tests I was on the borderline of needing a transplant, the numbers were close but not close enough. I was happy to escape the situation.

Unfortunately, worse was to follow as scans showed a growth in my Uterus, the size of a fist. I had no idea at all, what a shock, and this had to be dealt with before anything else.

As I was in a frail state, the operation was going to be risky even before it was confirmed if the lump was nasty or not. Thankfully the operation went to plan, the growth was not cancerous, however left to its own devices I could have been in trouble. Now, that was finished I could get back to the normality of life, or thereabouts.

A couple of years further down the track, as the children eased into their early teens and were able to come home from school by themselves and as our dog breeding was scaled back, I decided to go back to work full time.

I got a position as an office manager for two retail outlets who supplied steel. I loved this position. The staff were lovely, I had an understanding boss and I could even walk to work. Everything was great, even the coffee. I wondered perhaps if was time to maybe save some money and go on a holiday.

Well, this day dream ended abruptly – just as I learnt that my boss was really happy with my performance and work ethic, disaster struck.

My defibrillator had started to do what it was supposed to do – putting my heart back into rhythm after an episode. It happened when I was driving, thank goodness nobody was harmed, but it was scary.

I was taking sick days at work as I was feeling terrible and made an appointment to see my GP. Not only was my blood pressure 65/35, but I was also in Atrial Fibrillation. I did not even know what that was.

I was admitted to hospital for a cardioversion which resolved the issue at least temporarily, however it went on for several weeks, continuing to go into Atrial Fibrillation then Cardioversion.

My employer was so understanding and offered leave for the period of three months to get better and return to work. At this point it got really serious and I started to have a heart attack. My children witnessed this which really broke me but I stayed strong for them.

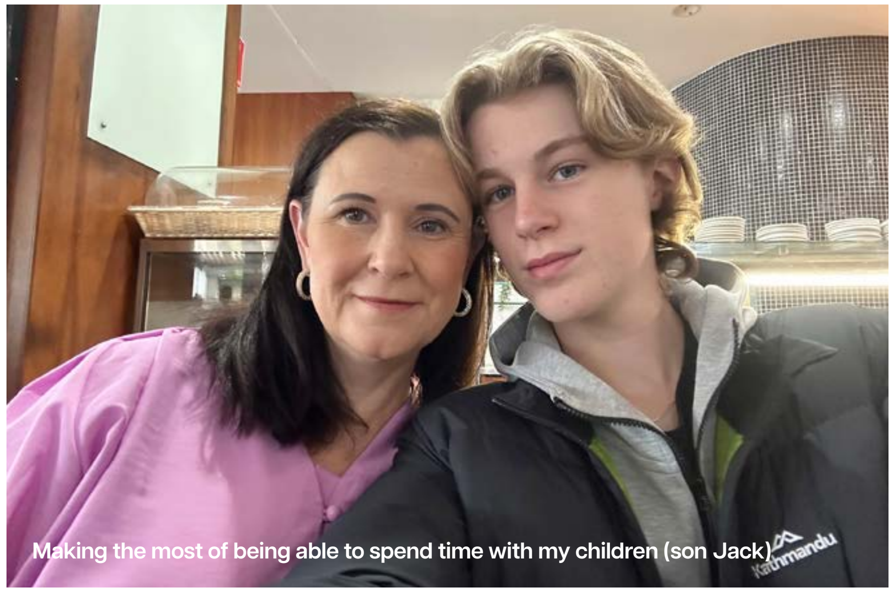
During the next appointment with my specialist, urgently arranged, I was told that my heart was so damaged that a heart transplant was the only possibility.

As a bridge to transplant, my surgeon tried to install a pacemaker, but this was unsuccessful as the wire was unable to be placed into my heart. The surgeon struggled for hours to no avail.

Heavy medication was the last choice I had. At this point of time, I had to resign from my position. Everyone was disappointed and concerned.

Off to the hospital I went for a week to have the work-up done for my impending transplant, with many tests carried out.

This was a particularly challenging time for me as my children, both under 16, were not permitted to visit me due to COVID restrictions.



Making the most of being able to spend time with my children (son Jack)

Another curve ball then hit – one of our beloved German Shepherds was in a terrible traumatic accident which took her life. My youngest son found her early in the morning.

I was extremely saddened by her death and I became even more destressed due to the fact my son was traumatised by this incident. After speaking to one of the nurses she applied for an exemption so my children could come visit. I was so happy to see my kids when it was approved.

The work-up for the transplant took a few months with a visit to St Vincent's Hospital being part of the process, to meet the staff and undergo further tests.

Finally, I was on the waiting list for a heart transplant.

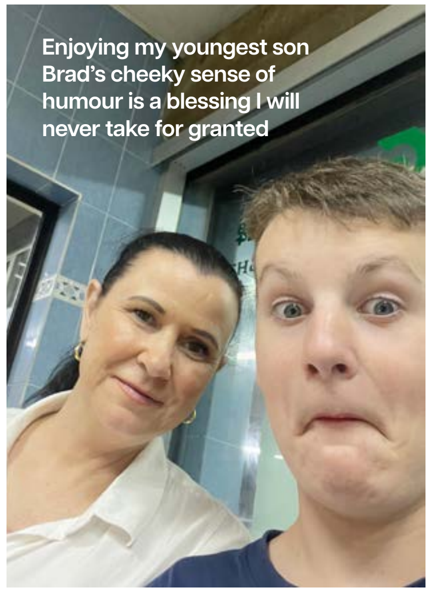
Incredibly I got a call the next day. I jumped onto a plane and travelled to Sydney. I will never forget saying goodbye to my children at the airport.

When I arrived at the hospital I was informed the heart was not viable. The hospital offered to organise a room that we could stay in overnight as it was late afternoon by then, however I declined the offer as I wanted to return to Adelaide as soon as I could.

Over the following months I tried everything I could to stay healthy and move around as much as I could. It was so difficult to conduct everyday chores by this stage, however I was grateful that the medication prescribed to me was working and kept me out of hospital.

Waiting for that phone call again was hard. It did get to a point after a few months when my family were really hoping for the call, but the wait gave me an opportunity to get better.

It was April, my son's birthday was approaching and something that I did not want to miss. We had a family dinner on the Saturday night and we arrived home at around midnight. Low and behold I received the call at 5:30am that day.



Enjoying my youngest son Brad's cheeky sense of humour is a blessing I will never take for granted

I answered the phone and they said "we have a heart for you" and was instructed on my travel arrangements. As I hung up my phone, I turned to see that my children were standing there with a mixture of relief and fear. I did not want to say, "everything will be fine", I told them that no matter what happens, I will fight and give it my all.

After my arrival at the airport I boarded the bus and was taken directly to St Vincent's Hospital. The staff there were so amazing, it was overwhelming. I felt that I was in safe hands and I was taken off to surgery.

I woke up, and I was very happy that I did despite being in ICU. I was lying flat with one pillow – I could breathe, no cough – It was incredible.

I had a nurse at my side reassuring me that everything went great. I felt this was a new life but my mind realised that someone, a family, was mourning a loved one. Not only was I given this priceless gift but my children, family, friends and everyone in my future who will care for me were blessed.

I was out of hospital in two weeks and doing well. We managed to get an apartment that was within walking distance to the hospital and only steps away from supermarkets, cafes, chemist and best of all, a fantastic remedial massage place that I wanted to go to.

Unfortunately there was a curve ball thrown at me with force. I went downhill in a matter of hours. I was rushed back to the hospital. I later found out I had fluid and blood clots building up in my heart cavity and my Tacrolimus was at a toxic level. Within no time at all, I was back in surgery in an attempt to fix this issue.

After this procedure I was back in a ward for the next two weeks where I contracted an infection in my throat. This infection caused many ulcers – I was unable to eat and drink for around a week. Luckily, I was able to suck on ice. This was the most painful experience I have ever had. This was really hard.

I woke up in the middle of the night, just moving, sitting up and with numerous intravenous lines as I was unable to take my medication orally. I felt like I'd had enough and wanted out but my mind again turned to my donor's family and imagined how they would be feeling. I said to myself "I'll get better, their loved one will not." I really feel their strength got me through.

Out of hospital again and back to the privacy of my apartment. So glad to have some real food. My muscles had wasted a lot. I had falls, but thankfully no harm done. I was on the road to recovery and getting home. I walked every day and worked hard to get home.

I was well enough at one point to go on a short ferry ride. How wonderful it was to feel fresh air, sea spray and a little sunshine. Another trip to Cronulla on the train – the sea, the scenery and managed to sneak in some delicious hot chips, they were the best.

Unfortunately, COVID had set in and there was an outbreak in Bondi which was close to where we were living. Of course we immediately chose to keep ourselves in isolation. This played in my favour as I used this for leverage to go home, maybe early.

My doctor explained to me that if the next round of tests were positive I could go home, two weeks early! The moment we got the go ahead, we were on the plane the next day, homeward bound for SA.

Seeing my children on arrival back in Adelaide was pure magic. Being in my home, my own bed and familiar surroundings was unreal. I was on a path to a new life.

To celebrate our new beginning and my positive recovery coming into my second anniversary post transplant, our family booked an overseas trip to Singapore, Thailand and Kuala Lumpur. As you can imagine, I was concerned about my health and accommodating my medications to those countries, but with plenty of planning and taking ample supplies, everything worked out. It was a holiday to remember.

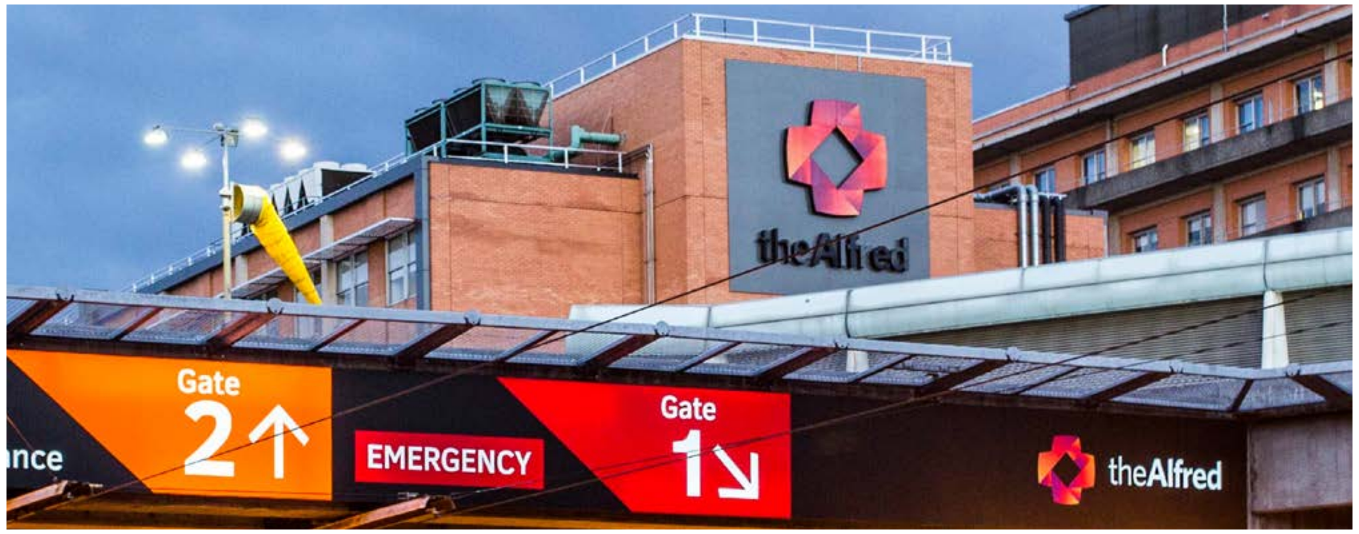
Railay Beach, Thailand

People are surprised and at times distressed to hear my story. How did you get through this? Why did this happen? How awful for you.

My reply is that I feel like the luckiest person alive. Every day I wake up it is a blessing. I was privileged to have this opportunity and my health condition disappeared overnight.

My ejection fraction prior to transplant was 22. My first ultrasound showed my ejection fraction was 55-60 and has been stable since. This was inconceivable, what did I do to deserve this?

In closing I would like to say that I am forever grateful for this experience. There are people, millions of people, who are suffering horrific situations that cannot be changed and there is no cure. These people are always in my prayers.



Recent news around AlfredHealth

In case you missed it...

Heart partnership to drive cutting edge care

6 July, 2023 | Stephanie Carson

Heart patients of the future are set to benefit from a new partnership which will bring together the combined strengths of three leading institutions in cardiovascular research and patient care.

Launched today, the Monash Alfred Baker Centre for Cardiovascular Research will build on the many significant advances in cardiovascular medicine and surgery already achieved by specialists at The Alfred, Monash University and Baker Heart and Diabetes Institute, to tackle some of Australia's most significant and emerging cardiac issues.

Professor David Kaye, Director of Cardiology at The Alfred and inaugural director of the new centre, said the formalised partnership will become a hub for the next generations of leading clinicians and researchers, as they work together to break new ground in the treatment of heart failure and heart disease.

"Our three organisations have a long and proud history of together translating research into health care that saves lives," Prof Kaye said.

Prof Christina Mitchell, Prof David Kaye, Prof Tom Marwick and Prof Andrew Way at the launch.

"This new partnership now means we can continue to achieve more together, using big data and first in human clinical trials to ensure patients receive cutting edge care."

Alfred Health chief executive Prof Andrew Way AM said the centre is a great reflection of what can be achieved through collaboration in health care.

"The care we deliver to our patients has evolved over decades and, at the core, has mostly only been advanced through innovation driven by leading clinical scientists," Prof Way said.

"I look forward to seeing what this great partnership between university, research institute and one of Australia's great public health services can achieve."

The Alfred, Monash University and Baker Centre are part of the Alfred Research Alliance, a collaborative community in Melbourne, dedicated to excellence in medical research and education.

'Heart in a box' now a proven gamechanger

21 April, 2023 | Stephanie Carson

Two Alfred heart experts have today declared a new method of donor heart preservation a gamechanger for heart transplantation in Australia and New Zealand.

Presenting the findings of their two year study, Prof David Kaye and Prof David McGiffin have told the International Society for Heart and Lung Transplantation meeting in Denver that hypothermic machine perfusion can safely keep donated hearts alive outside the body for almost up to nine hours - more than double the current standard time using ice slush.

The technique works by continuously cooling a retrieved donor heart at 8°C while supplying it with a nutrient-rich oxygenated solution.

Prof Kaye says this represents a significant breakthrough in the number of hearts that can be transplanted in Australia, given the vast distance between capital cities.

"We hoped that the procedure, originally developed in Sweden, would lengthen the time limit from less than four hours for traditional storage using ice, however this was yet to be confirmed in a clinical study," Prof Kaye said.

"With clinical evidence we now know that the donor heart is better protected with ex-vivo perfusion as opposed to ice slush in a cooler."

Prof McGiffin and Prof Kaye with the machine

Prof Kaye said the patients in the trial had recovered well, which could be in part attributed to the nutrition and oxygen provided to the donor heart by the perfusion system.

"The best chance that a patient has of surviving heart transplantation is if they come out of the operating room with a well-functioning heart despite a very, very long ischemic time, and that's what the results have shown."

Several sites across Australia and New Zealand were part of the trial, with The Alfred the first to perform five transplants.

Other sites included the Royal Children's Hospital Melbourne, St Vincent's Hospital Sydney, Fiona Stanley Hospital Perth and Auckland City Hospital in New Zealand.

Pre-clinical research was led by the Critical Care Research Group in Brisbane.

XVIVO Perfusion in Sweden developed the non-ischemic heart preservation method being used in the study.

Happy hearts: top heart health tips for women

14 February, 2023 | Stephanie Carson

Two Alfred heart experts have today declared a new method of donor heart preservation a gamechanger for heart transplantation in Australia and New Zealand.

There's no better day to consider matters of the heart than Valentine's Day.

Dr Monique Watts, Head of The Alfred's Women's Heart Clinic, says when it comes to heart health, it's particularly important for women to pay attention.

"Most women aren't aware of their risk of heart disease," Dr Watts said.

"Heart disease is the number one killer of women worldwide, and too often is under recognised and under treated."

Dr Watts said that while women with families or busy work lives may find it tempting to put their own health needs to the side, there are some simple habits that can be factored into your day to help protect your heart:

Top tips for heart health for women

- Keep moving: It can be hard to fit in scheduled activity at the gym, but incidental exercise can be just as beneficial. Taking the stairs, walking around the block during your lunch break or joining the kids on a bike ride all help to maintain cardiovascular health.
- Manage stress: While a short guided meditation can calm your nervous system, it's not for everyone. Dr Watts says managing stress can be as simple as asking for help. "Perhaps there's a friend you can share pick up duties with, or if it's an option, delegate more tasks in your household to help manage the load. Schedule time for you to look after yourself."
- Go to the doctor: If you notice something unusual, go to the doctor. "It's easy to put off making an appointment when the issue doesn't seem urgent," Dr Watts said. "But if you get on top of your health early, heart disease can be prevented."
- Prioritise yourself: Always pack a healthy snack for the kids? Remember to pack one for yourself too. "It's so easy to put yourself last," said Dr Watts. "But looking after yourself is the best thing you can do for your health, and for those who love you."

Dr Monique Watts is encouraging more women to pay attention to their heart health

The Alfred's Women's Heart Clinic offers a streamlined service to assist timely diagnosis and specialist management of cardiac conditions more frequently seen in women while promoting healthy lifestyle and the prevention of heart disease for all Australian women.

Life-saving ECMO machine research receives major funding boost

29 September, 2022 | Tate Papworth

Intensive care specialists from The Alfred will play a major role in new research that aims to better identify patients who will benefit most from the advanced form of life support, known as ECMO (extracorporeal membrane oxygenation).

The Alfred will take the Victorian lead in the multi-centre $1 million study announced by Federal Minister for Health Mark Butler during a visit to the hospital's intensive care unit.

An ECMO machine takes over from a critically ill patient's lungs and heart when their own organs cannot function, by circulating blood through a machine outside their bodies.

The machine is typically only used on a patient for an average of fewer than 10 days, as a last-ditch treatment option.

But head of The Alfred's ECMO program A/Prof Vincent Pellegrino said a deeper understanding of the technology was developed during the COVID-19 pandemic.

"The motto we developed was just get us to 35 days, which we found to be a major landmark in the treatment," he said.

Continued on next page...

...Life-saving ECMO machine research receives major funding boost from previous page

"We only lost one patient out of 64 who had been on the machine for a minimum of 35 days."

The $999,779 Federal Government research grant, announced by on National Heart Day by Minister Butler, will allow specialists from The Alfred and other centres to further expand on recent lessons.

The 'PRecision Ecmo in Cardiogenic Shock Evaluation: PRECISE Study' will be led by Monash University, in collaboration with Alfred Health, St Vincent's Hospital Sydney, the University of Sydney, and The University of Queensland's Critical Care Research Group. It will recruit 236 patients to investigate whether biomarkers can better identify patients who will receive the best long-term benefit from ECMO.

One person who knows the benefits of ECMO more than most is Dean Barber.

The 53-year-old required the machine after suffering a heart attack while at work.

"I wouldn't be here today without ECMO, I can say that pretty confidently," Dean said.

"I'm incredibly lucky that when I had the heart attack I was close enough to a hospital with these machines."

"It's made me realise how lucky I am – I used to be a smoker but I've given that away and I'm happy to be spending quality time with my young kids."

www.alfredhealth.org.au

HLTTV

Heart & Lung Transplant Trust (Victoria) Inc.
Incorporated in Victoria A0037327C ABN 68 966 022 PO Box 25036, Melbourne VIC 3004

Notice of Annual General Meeting 2023

Tuesday 14 November at 7.30pm

Venue/Zoom will be confirmed with RSVP

Join us to acknowledge our achievements and elect new members to the committee

The business of the annual general meeting shall be:

1. Confirmation of Minutes of the 2022 AGM
2. Presentation of the 2023 Annual Report
3. Presentation of the 2023 Annual Financial Report*
4. Elect officers of HLTTV and the ordinary members of the committee; and
5. Confirm appointment of the auditor for 2022-2023
6. Any special business (if any)

The annual report and financial reports to be considered are available from the Secretary on request president@hlttv.org.au

The 2023 agenda and minutes of the 2022 AGM are available on our website in the Events, AGM section.

Any member intending to bring any other business before a meeting must notify the Secretary in writing, or by email to secretary@hlttv.org.au NO LATER than 7 November 2023.

Each member is entitled to appoint another member as a proxy by notice.

Please email the president@hlttv.org.au for the proxy form or download a form on our website in the Events, AGM section. You can complete and return the form to the President via email or hand it to the President before the time of the meeting.

*receive and consider the statement in accordance with the section 30(3) of the Act

If you plan to attend the AGM, please RSVP by Friday 14 November, 2023.

If you are unable to attend, and would like your apologies to be noted, contact the President, Tessa Keegel on or president@hlttv.org.au

www.hlttv.org.au @HLTTV

Circulator word search 1

Can you find all the words listed below?

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

CIRCULATOR
TRANSPLANT
LUNGS
HEART
ECMO
ADMISSION
ANAESTHETIC
BLOOD
OXYGEN
ALFRED
SURGEON
NURSE
RECOVERY
REHAB
GYM
MEDICATION
IMMUNE
NEEDLE
ICU
DISCHARGE
CLINIC
BIOPSY
BRONCHOSCOPY
GRAFT
RECIPIENT
DONOR
ORGAN
TISSUE
INFECTION
ARTERY
SCALPEL
PULSE
PILL
THEATRE
SCRUBS
PRESSURE
DOCTOR
FAMILY
LIFE
TABLETS
ANNIVERSARY
RESPIRATORY
RENAL
HOSPITAL
DIALYSIS
MASK
EMERGENCY
BREATH

Word search solution on the next page...

The Mechanic and the Cardiologist

A Lexus mechanic was removing a cylinder head from the motor of a LS460 when he spotted a well known cardiologist in his shop. The cardiologist was there waiting for the service manager to come and take a look at his car when the mechanic shouted across the garage, *"Hey Doc, want to take a look at this?"*

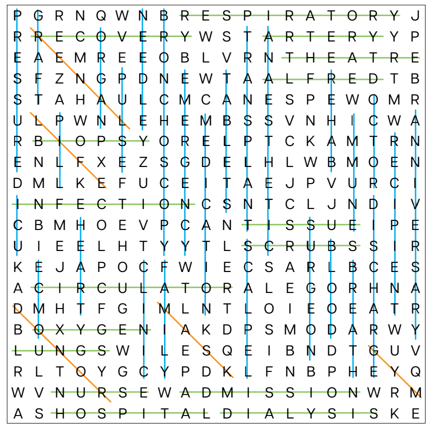
The cardiologist, a bit surprised, walked over to where the mechanic was working.

The mechanic straightened up, wiped his hands on a rag and asked, *"So Doc, look at this engine. I opened its heart, took the valves out, repaired or replaced anything damaged, and then put everything back in, and when I finished, it worked just like new. So how is it that I make $48,000 a year and you make $1.7M, when you and I are doing basically the same work?"*

The cardiologist paused, leaned over, and then whispered to the mechanic... ***"Try doing it with the engine running."***

Circulator word challenge 1 solution

from page 61



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

IMPORTANT DATE TO REMEMBER

Membership renewal 2023–2024

HLTTV membership fees were due on 1 July 2023 for the 2023–2024 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 $15 membership fee will greatly assist HLTTV to continue their wonderful work supporting heart and lung transplant patients.

IMPORTANT DATE TO REMEMBER

Save the date for HLTTV Xmas BBQ

Sunday 26 November 2023 | 11.30am to 2.30pm

HLTTV 2023 Xmas BBQ will be held in Fawkner Park, adjacent to The Alfred again this year to celebrate and connect heart and lung transplant recipients.

The HLTTV Christmas BBQ is a great social event for pre and post transplant patients, families, carers and friends. BBQ and drinks are provided (including vegetarian options). Great raffle prizes offered on the day – donations can be left at 5th Floor Reception at The Alfred.

Please contact Martina on 0409 957 492 or email martina@hlttv.org.au

www.hlttv.org.au

Are you involved in a business which could provide discounts on goods or services for HLTTV members?

We're looking to increase benefits for our members and we'd love to hear from businesses that would like to get involved with the work we do either through the provision of discounts or supporting us in other ways.

Reach out to Tessa on president@hlttv.org.au to discuss how to get involved

FACT

454 people became organ donors in 2022

FACT

There were 117 heart donations in 2022

FACT

There were 142 lung donations in 2022

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 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.

IT TAKES 1 MINUTE TO REGISTER. IT COULD GIVE ME A LIFETIME.

REGISTER AS AN ORGAN & TISSUE DONOR AT DONATELIFE.GOV.AU

donatelife

JENNY IS ON THE WAITLIST FOR A HEART AND LUNG TRANSPLANT