the Circulator

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

Autumn Edition | 2021 | Issue No. 103

President's message

Welcome to the Autumn 2021 Circulator. It's hard to believe it's been a year since all our lives changed. In my house, my husband was advised to work from home due to his post-transplant, immune-compromised status.

We never could have imagined how different life could be over a year later. Still (mostly) working from home, and feeling the 'Pandemic fallout' in so many unexpected ways.

But here we are, 12 months later and I'm thrilled to see our corner of the world opening up again.

We're still wrestling with the logistics of COVID-safe face-to-face get togethers for HLTTV members. We know how important that peer connection is and are working hard on options to get the gang back together.

I was starkly reminded of this recently, when I learnt that one of HLTTV's most cherished committee alumni had passed away. Claire Stubber was an absolute light on this earth, and will be incredibly missed. We're so grateful to her husband Ian who has been kind enough to share a favourite photo and some poignant thoughts as part of our tribute to his soulmate, as has former HLTTV President Louisa Walsh, and Claire's research colleague, Maggie Kirkman.

In her reflections about Claire, Louisa highlights how important and inspirational it is to see someone like Claire surviving and thriving after transplant. From a personal perspective, both Louisa and Claire are incredible inspirations to me and my soulmate.

If you'd like a deep insight into one of Claire's many acts of generosity and intellect, I ask that you take the time to watch the videos of transplant experiences that she led and appeared in. These videos are a resource for both people facing transplant and health professionals wanting to learn more about life with transplant.

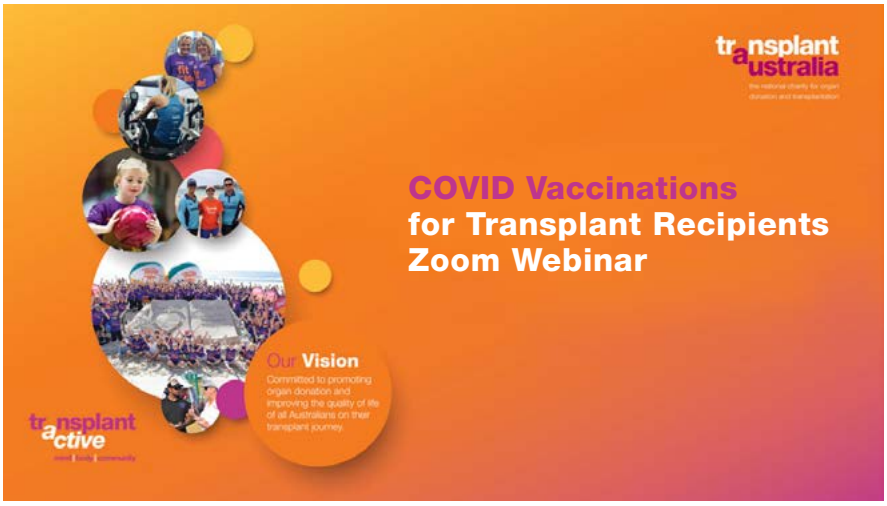
You can access the *'Transplant Stories'* from the home page of the HLTTV website or go to: https://www.hlttv.org.au/news-resources/transplant-interview-videos/videos

Also in this edition, you'll see we've pulled together some information on the COVID-19 vaccines – while we look forward to receiving 'formal' directions/advice from the Alfred, in the meantime we recommend watching the Transplant Australia webinar which can be found on their website (see below).

Here's hoping that these cooler Autumn months continue to be COVID-safe and that we can meet in person again soon.

Yours in good health,

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



https://transplant.org.au/living-with-your-transplant/self-care/covid-19-and-transplant-recipients/

Michael Billings is an Australian Commercial Radio Awards (ACRAs) award-winning radio announcer (Best On-Air Team 2017) with almost 10 years on-air experience in Broome, Mildura and Bendigo.

Michael is currently Workday Announcer for Hit FM 91.9 (Southern Cross Austereo) in Bendigo.

The ***Let's Talk Organ and Tissue Donation*** podcast is a very personal project for Michael, after losing his father while on the wait list for a liver transplant.

"My dad died in his 60's waiting on a liver transplant, so this is a project that's very close to my heart," says Michael.

"After losing my father before he had an opportunity to receive a liver transplant, I have learnt there are so many facets to organ donation. The one thing that never ceases to amaze me is the selflessness of families who choose to think of others amidst their own grief. It's the greatest act of generosity," he says.

"This podcast literally has the potential to save lives."

Michael currently resides in Bendigo with his wife and two daughters.

donatelife

Get a visual taste of this brand new podcast from DonateLife and Michael Billings on page 20.

Secretary's message

Hello everyone! I hope this finds you well and as we are already into 2021, it seems a bit strange to say *Happy New Year!* but such is the nature of publishing a quarterly magazine. I hope the year has started well for you and yours.

As I nervously went back to my local gym today, it seemed like nothing had changed, the same Saturday crew there with swimming lessons in full swing and a crowded carpark. The gym has always been strict about hygiene and wiping down machines and with hand sanitizer available but there are other *CoVidSafe* protocols in place, which made me feel a little easier about being there. I did wear a mask, as a few others did too, and respectfully people were keeping their distance and the machines had been spread apart. So, after organizing my senior's discount, I got back on that bike and pedaled until my legs gave up!

We have had a chance to enjoy a couple of getaways this year. A lucky opportunity to get a Victorian Travel Voucher inspired us to go to Bright for a few days of perfect weather, river swimming, reminiscing about James riding up to Falls Creek in the *Tour de Transplant* 2014 and 'no' he didn't want to do it again! We did hire bikes and rode to Wandiligong for a coffee and watched the hang-gliders in the wonderful clear skies on our way back.

We were lucky also to have booked our annual family stay in Anglesea with our kids and friends, which was a relaxing fortnight with sunny days, warm water, good food, books, crosswords and lots of playing card games.

So now, what is there to look forward to? How is everyone feeling about a catchup?

Now that current restrictions have eased and vaccinations being rolled out there may be opportunity for safe face to face connections as well as online events. With Easter at the beginning of April and the snap lockdown, the Committee decided at the February meeting, we were not able to organise an Easter BBQ.

Let me know if you have any ideas on ways to connect our members – locally or regionally. All members are welcome to attend our Committee meetings, please see the list of 2021 dates and contact me for the meeting details. Meetings have been online via Zoom recently.

Regards to all and hope your year has started well!

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

Did you know? in 2020

- Victoria was the state with the most blood donations
- Melbourne CBD was the centre with the most blood donations (68,753)
- Red Cross Lifeblood served 160,000 cups of tea and 280,000 biscuits

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When we approached Ian Stubber about a tribute to his beautiful wife Claire who passed away late last year, his message was simple.

"All the wonderful things that people are saying about Claire are true. Claire was a beautiful person inside and out, and she was my soulmate. My life was better from the moment I met her."

Claire had an amazing impact on so many people, and HLTTV has benefited beyond measure from both her and Ian (an incredibly talented photographer) for close to a decade. From writing and editing the *Circulator,* through to coordinating and riding in the inaugural Tour de Transplant and many, many activities in-between.

She will be missed.

VALE

DR CLAIRE STUBBER

Adjunct Research Fellow,
Global and Women's Health, School of Public Health and Preventive Medicine

15 August 1978 – 23 December 2020

Dr Claire Stubber has died at the age of 42. She was a remarkable woman and scholar.

Claire was aged 17 when she came to the Alfred Hospital from Perth to prepare for receiving a donated heart and lungs, after a lifetime of increasing debilitation resulting from a rare pattern of congenital cardiac defects. Claire has said that she felt death approaching; her doctors in Perth had told her parents to take her home and love her. Claire remained grateful that her parents in addition sought organ transplantation on her behalf.

Claire's transplant surgery was in October 1996; it gave her 24 years of extra life. Although she continued to have problems with her health that saw her in and out of hospital, Claire made the most of her life and loved what these extra years allowed her to do, such as read, think, and write; become an aunt; enjoy a happy marriage; and contribute as a valued member of an academic group.

Despite her disrupted schooling, Claire completed a PhD at the University of Western Australia. In her PhD thesis she analysed Mary Shelley's novel Frankenstein and compared it with her own life story as a person constructed from body parts [https://research-repository.uwa.edu.au/en/publications/reconstructed-bodies-a-fictocritical-consideration-of-the-persona]. Claire then came to Melbourne to live, to be near The Alfred.

It was a great day for Global and Women's Health when, in 2014, Claire sent her CV to us. We met her and thought that she could bring an original perspective to our work in public health. Indeed she did. Her literary skills contributed to qualitative analysis, to clarity in many papers produced by the team, and to our weekly work-in-progress seminars. Recently, she co-authored a systematic review of qualitative research on recipients of donated hearts and/or lungs [https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0241570]. It included a summary of the adverse effects of receiving organ donation, such as cancer, rare infections, diabetes, and elevated cholesterol; Claire commented to her co-author, Maggie Kirkman, that she had experienced them all.

Claire's most recent work, and that to which she was most committed, was to ensure that people confronting the prospect of receiving a donated heart or lungs could watch videos on the internet of recipients prepared to describe their experiences in detail. She (with Maggie Kirkman) completed six lengthy interviews and uploaded them in a format that made them searchable [https://www.hlttv.org.au/news-resources/transplant-interview-videos/videos].

Claire contributed her own story to the collection. This initial work was funded by the Grenet Foundation through Ann Hyams. Claire's colleagues are determined to seek further funding to extend and refine this project.

Claire met the man who was to become her husband, Ian, while they both prepared for transplantation. Ian received lungs to ameliorate the effects of cystic fibrosis. Theirs was a close partnership in which their different interests were shared. Ian is a photographer who specialises in cosplay (in which people wear costumes associated with a character from a game or film); Claire acted as his assistant. In turn, Ian set up recording equipment before each interview with a transplant recipient.

Claire was admitted to hospital in September 2020 and suffered diverse and increasing setbacks until her death two days before Christmas. Her family was with her. She is survived by her husband Ian Stubber, parents Barbara and Leo, sisters Anne, Eve, and Zoë, and her sisters' families. Her friends and colleagues, while mourning her loss, are grateful to have worked with Claire and to have benefited from her generous warmth, her insight, her sense of humour, and her scholarship.

Dr Maggie Kirkman PhD MAPS
Senior Research Fellow
Global and Women's Health, Public Health & Preventive Medicine, Monash University

I was extremely sad to hear of Claire's death just before Christmas 2020.

Claire, and her husband Ian, were such fixtures in our small community of transplant recipients. They were two of the first people I got to know well after my transplant, and Claire's presence in our community just seemed like something that had always been, and always would be.

I first really got to know Claire through the Heart and Lung Transplant Trust, and specifically, working together with her to plan a trivia night.

We got to know each other even better through the first *Tour de Transplant* in 2014, where we were part of a small group delivering education sessions to schools and community groups along the route of the bike ride.

Claire was extremely open with her transplant story, was an excellent public speaker, and loved speaking to classes of kids about her experiences.

Claire was also very generous with her time and knowledge. She was a volunteer for the Heart and Lung Transplant Trust, but she was also an adjunct research fellow at Monash, which meant that a lot of her ground breaking research work was unpaid. This included the series of videos of transplant experiences that she led and appeared in, which are a resource for both people facing transplant and health professionals wanting to learn more about life with transplant.

This generosity of spirit and willingness to share her knowledge for the good of others in her community are an important part of Claire's legacy.

For me, personally, it was very inspiring to know Claire. As a new transplant recipient it was amazing to get to know someone who was still going strong after being transplanted in the early days. Someone who had worked, studied, travelled and really embraced life.

Knowing Claire and Ian helped with some of the fear and 'what ifs' – I could always looks to them as examples of long and joy-filled post-transplant lives.

Finally, and most importantly, Claire was just a lovely friend and it was a privilege to get to know her, work alongside her, and share a few dumplings along the way. She was intelligent, funny and wise, and will be greatly missed.

My heart goes out to Ian, Claire's family, and everyone in our wider transplant community who knew her, and has now lost someone who was so loved.

Louisa Walsh
former HLTTV President

Trust the science and listen closely to your health team

When deciding to get the COVID-19 vaccine, it's important you get your information from credible, evidence-based sources.

There is always some degree of hesitation when it comes to the unknown, especially when it can have an effect on your wellbeing.

However the overwhelming priority for every transplant recipient must be self preservation. Preventing the debilitating and sometimes catastrophic effects of acquiring COVID-19 takes on a much higher degree of priority than the very small degree of risk when taking the vaccine that prevents it.

Except for an infinitely small number of cases, accepted world-wide data currently indicates that none of the vaccines approved for use in Australia cause serious side effects for immunosuppressed recipients of the vaccine.

It is widely acknowledged by all Australian Federal, State and Territory health authorities that vaccines approved for use in Australia are SAFE and recommended for use by transplant recipients in 'PHASE 1b' of the Australian national rollout program.

Protect yourself and the community

Vaccination is the most effective way to protect against infectious diseases.

IMPORTANT:
Immunosuppressed people including heart and lung transplant recipients are part of 'PHASE 1b' of the national vaccine rollout.

Vaccines strengthen your immune system by training it to recognise and fight against specific viruses.

When you get vaccinated, you are protecting yourself and helping to protect the whole community.

Help reduce COVID-19 in the community

COVID-19 can spread quickly and widely. It has resulted in the deaths of over 1.9 million people worldwide and over 900 deaths in Australia.

When enough people in the community are vaccinated, it slows down the spread of disease. Achieving herd immunity is a long-term goal. It usually requires a large amount of the population to be vaccinated.

Studies will monitor the impact of COVID-19 vaccines in Australia and whether herd immunity is developing over time.

For this reason, public health practices will stay in place until evidence shows that:

- vaccination prevents transmission and
- herd immunity is achieved in Australia.

The best strategy to manage the potential public health risk posed by incoming travellers to is mandatory quarantine with regular COVID-19 testing.

Vaccination rates in Australia

Australian families demonstrate that we are a vaccination nation. Childhood immunisation rates reached record levels of 95.09 per cent for all 5 year old children at December 2020.

Reaching our vaccination target of 95 per cent supports herd immunity to slow down the spread of vaccine-preventable diseases.

For other vaccines, when lots of people in the community are protected by immunisation, we rarely see the deadly diseases they prevent. This includes diseases such as diphtheria, measles and meningococcal disease.

It is not yet known if we can eradicate COVID-19. The first step is to reduce the harm it causes and its spread in the community.

High immunisation rates also protect vulnerable people in our community who cannot be vaccinated, such as very young children or people who are too sick.

Higher vaccination rates makes outbreaks much less likely. It also reduces the need for preventive measures, such as border closures and travel restrictions.

This will reduce the health, social and economic impacts of the COVID-19 pandemic.

www.health.gov.au

COVID-19 VACCINATION
Safe. Effective. Free.

LEARN MORE ABOUT COVID-19 VACCINES
www.health.gov.au/initiatives-and-programs/covid-19-vaccines/learn-about-covid-19-vaccines

ASTRAZENECA

What ingredients are in the vaccine?
Active – Recombinant, replication-deficient chimpanzee adenovirus vector
Inactive – Histidine; Histidine hydrochloride monohydrate; Sodium chloride; Magnesium chloride hexahydrate; Disodium edetate (EDTA); Sucrose; Ethanol absolute; Polysorbate 80; Water for injections

How many doses will you need?
Two – administered 4-12 weeks apart.

How many doses will Australia receive?
The Federal Government has purchased 53.8 million doses – 50 million doses will be manufactured in Melbourne with the remaining 3.8 million doses produced in Europe.

How effective is the vaccine?
62% effective preventing laboratory confirmed COVID-19 when dosed 28 days apart; 82% effective when doses are spaced 12 weeks apart; 76% effective at preventing COVID after a single shot; reduced transmission of the virus by 67% in the UK.

Side effects – ***All injectable vaccines have the potential for an allergic reaction after you are injected.***
Serious side effects – Rash; itching or hives on the skin; swelling of the face, lips, tongue or other parts of the body; shortness of breath, wheezing or difficulty breathing; fainting, dizziness, feeling lightheaded (due to a drop in blood pressure).
Less serious side effects – Tenderness, pain, warmth, redness, itching or swelling where the injection is given; generally feeling unwell; feeling tired (fatigue); chills, fever or feeling feverish; headache; feeling sick (nausea); muscle pain/ache, joint pain.

PFIZER BIONTECH

What ingredients are in the vaccine?
mRNA, lipids (4 hydroxybutyl, azanediyl) bis (hexane-6.1-diyl) bis (2-hexyldecanoate), 2[(polyethylene glycol)-2000]-N, N-ditetradecylacetamide, 1.2-distearoyl-sn-glycerol-3-phosphocoline and cholesterol), potassium phosphate, sodium chloride, dibasic sodium phosphate dihydrate and sucrose.

How many doses will you need?
Two – administered at least 21 days apart.

How many doses will Australia receive?
The Federal Government has purchased 20 million doses produced in Belgium and Michigan (USA).

How effective is the vaccine?
95% effective against symptomatic COVID-19; 52% effective at preventing illness after the first shot.

Side effects – ***All injectable vaccines have the potential for an allergic reaction after you are injected.***
Common – Pain or swelling at the injection site; tiredness; headache; muscle pain; fever and chills; joint pain.
Less common – Redness at the injection site; nausea; enlarged lymph nodes; feeling unwell; pain in limb; insomnia; itching at the injection site.
Rare – Severe allergic reaction (anaphylaxis).

Only 11.1 people in every one million suffer anaphylactic reaction – that's 0.000011%.

www.health.gov.au (as at 28 April 2021)

Note: the Novavax vaccine is yet to be approved for use by the TGA

IMPORTANT: If you are taking, have recently taken or might take other medicines, blood thinners or vaccines or are immuno-suppressed it is highly recommended you tell your healthcare provider in order to determine if it is safe to take either of these vaccines.

ATAG comments on AstraZeneca side-effects and risk factors

The Australian Technical Advisory Group on Immunisation (ATAGI) recommends that the COVID-19 vaccine by Pfizer (Comirnaty) is preferred in adults aged under 50 years.

In people 50 years and over, ATAGI continue to advise that the benefit of vaccination with AstraZeneca COVID vaccine outweighs the risks associated with vaccination.

This recommendation is based on:
- the increasing risk of severe outcomes from COVID-19 in older adults (and hence a higher benefit from vaccination), and
- a potentially increased risk of thrombosis with thrombocytopenia following AstraZeneca vaccine in those under 50 years.

There appears to be a small risk of TTS in people 50 years and over, but this risk appears to be lower than in younger people. Cases overseas have been reported at all ages.

People who are considering vaccination with AstraZeneca COVID-19 vaccine should be aware of this potential complication as part of providing informed consent.

The COVID-19 AstraZeneca vaccine can be used in adults aged under 50 years where the benefits clearly outweigh the risk for that individual and the person has made an informed decision based on an understanding of the risks and benefits.

The COVID-19 Vaccine AstraZeneca appears to be associated with a rare side effect called thrombosis with thrombocytopenia syndrome (TTS).

What is TTS?

TTS involves blood clots (thrombosis) and low levels of blood platelets (thrombocytopenia). In Australia symptoms of TTS have occurred between 4 and 26 days post-vaccination.

The blood clots can occur in different parts of the body, such as the brain (called cerebral venous sinus thrombosis or CVST) or in the abdomen.

The mechanism that causes TTS is not fully understood, but it appears similar to heparin-induced thrombocytopenia (or HIT), a rare reaction to heparin treatment.

How common is TTS?

Overall the rate of TTS is estimated to be about 6 cases per million people vaccinated. But the rate is estimated to be higher (20-40 cases per million) in those under 50 years of age. These Australian estimates are not exact because there are very small numbers of TTS cases in Australia.

What symptoms does thrombosis with thrombocytopenia syndrome usually cause?

TTS is rare and occurs around 4-26 days after vaccination. Symptoms can include abdominal pain and/or severe headache that does not settle with pain relief. People should seek medical attention immediately if they experience these symptoms:
- a severe persistent headache with additional features
  - appears at least 4 days after vaccination
  - does not improve with simple painkillers
  - may be worse when lying down or accompanied by nausea and vomiting
- neurological symptoms such as:
  - blurred vision
  - difficulty with speech
  - drowsiness
  - seizures
- shortness of breath or chest pain
- a swollen leg
- persistent abdominal (belly) pain
- tiny blood spots under the skin away from the site of injection together with symptoms above.

www.health.gov.au (as at 28 April 2021)

To learn more about COVID-19 vaccines and risk factors associated with the AstraZeneca vaccine go to:
www.health.gov.au/initiatives-and-programs/covid-19-vaccines/learn-about-covid-19-vaccines/about-the-astrazeneca-covid-19-vaccine

LEARN MORE ABOUT COVID-19 VACCINES FOR PEOPLE WITH IMMUNCOMPROMISE

www.health.gov.au/resources/publications/atagi-covid-19-vaccination-decision-guide-for-people-with-immunocompromise

Q&A

transplant australia

The following information comes from an online Q&A from viewers after the Transplant Australia webinar – *Transplant Talks*

How will the anti-rejection drugs affect the body's response to the antigens in the vaccine?
We don't know for certain, but based on experience with other vaccines we predict the immunosuppressants (anti-rejection drugs) may reduce the response to COVID-19 vaccines a little, but predict the vaccine will still have effect.

Can people with immunosuppression safely take AstraZeneca vaccine?
Yes. The COVID-19 vaccines planned for use in Australia including the AstraZeneca vaccine are not live vaccines.

Adenovirus triggered/caused my chronic rejection in 2016 and I was finally re-transplanted towards the end of last year – am I safe to get the AstraZeneca vaccine?
Unlike adenovirus infections, the adenovirus vector in the AstraZeneca vaccine does not replicate (multiply/proliferate). We do not predict that it will cause organ rejection.

What percentage of people who undertook the vaccine trials were transplant (specifically kidney transplant) patients and what was the outcome of the trials on those people?
Transplant patients were excluded from the COVID-19 vaccine trials to date. We have preliminary data from John Hopkins Medicine suggesting vaccination does not cause different side effects compared to the regular population. COVID-19 causes severe disease in transplant patients, so we strongly suggest you get the COVID-19 vaccine offered to you.

Are children of Transplant recipients going to be given separate advice regarding vaccination, or will they be treated as per "ordinary" children?
From the information available to us at this time, we think family members of transplant patients (including children who have had transplants) will have to wait for their turn to be vaccinated. Even children who are immunosuppressed have a low rate of serious COVID-19 infection compared to immunosuppressed or elderly adults.

What about patients waiting for transplant? Where do they fit?
Patients waiting for transplant will be prioritised for vaccination like transplant recipients. They are in phase 1b of the vaccine rollout.

If Pfizer has not tested for immunocompromised, how could the post transplant be suitable?
Based on experience with other vaccines we predict the immunosuppressants (anti-rejection drugs) may reduce the response to COVID-19 vaccines a little, but predict the vaccine will still have effect. We do not expect any different side effects compared to the general population nor do we expect vaccine to cause organ rejection – this is supported by preliminary results from John Hopkins Medicine.

How long will infection control occur after the second vaccination? Will we need a vaccine annually as we do for the flu vaccine?
Protection in the trials has been examined for about two months so far, but we will get more information as individuals in the trials are followed for longer. It is likely that further doses of vaccine are required in future.

What do we need to do after receiving the vaccine?
You can be less anxious about being infected with COVID-19, but until a lot of the population here and overseas is vaccinated and we have further information of protection by the vaccine in transplant patients, you still need to wash your hands and socially distance.

Is there any data on how the various vaccines interact with eachother? As an example, if you have the Pfizer vaccine initially and complete that course, and then get the AstraZeneca or other vaccine other than Pfizer the following year (or whenever the booster is recommended) does this impact on vaccine efficacy or health of transplant patients?
Use of different vaccines in the same person has not been tested yet, but this is the subject of planned trials.

Which group will caregivers or close family contacts of transplantees fit in? In 1b, along with us?
Family contacts or caregivers do not move up the vaccine queue because they have a transplant patient as a contact, so they will have to wait until their time for vaccine is due.

Do I need to have this vaccine? I would prefer not.
COVID-19 can cause serious disease in transplant patients, so we strongly suggest you are vaccinated when this is offered to you.

Will my wife get the vaccine at the same time as me or will she have to wait being she is of good health and in her 30's?
She will have to wait.

Are there any early results coming in from the John Hopkins study in the US on vaccines in transplant patients?
Early results suggest the vaccine did not cause organ rejection and side effects were similar to the general population.

Given that the annual flu vaccine will be distributed at a similar time to the covid vaccine for group 1b, should we be having the flu vaccine first, before covid vaccine?
For caution it is recommended that influenza vaccine and COVID-19 vaccines are separated by 14 days but if they are given closer together we don't expect this will cause any problems.

Given the immunosuppressed state of transplant patients, what sort of protection can we expect from the vaccine – using Pfizer vaccine's 95% efficacy as a guide, would we expect maybe 50% efficacy?
It is difficult to estimate vaccine effectiveness in transplant patients, so we will have to wait for this data, but we do expect protection against COVID-19 particularly severe disease, as has been seen in the trials in the general population.

After the first two doses, what is planned as to the next shot to be received, given duration of protection unknown?
Protection in the trials has been examined for about 2 months so far, but we will get more information as individuals in the trials are followed for longer. It is likely that further doses of vaccine are required in future.

My wife was a kidney donor, which phase does she fit in?
Unless she has other medical illnesses, she will likely be offered vaccine based on her age.

Does type of transplant make a difference regarding COVID? eg. Is someone with a corneal graft of more or less risk than someone with a transplant requiring blood matching?
Some organ transplants are at higher risk of serious COVID-19 disease, such as lung transplants. Broadly

speaking, the more intense the immunosuppression, the higher the risk of severe disease.

What is the efficacy difference between live vaccine and non-live" vaccine?
Live vaccines can be dangerous for immunosuppressed patients like transplant patients, but all the COVID-19 vaccines planned for Australia are not live vaccines.

Will patients on dialysis be treated similar to transplant patients and are there other factors that need to be considered when getting the vaccine?
Patients on dialysis will be in phase 1b like transplant patients.

Are donors checked for covid?
Yes donors are routinely screened for COVID-19 infection.

Do the stats presented for kidney transplant recipients include SPK transplant recipients?
The data of risk for serious COVID-19 infection in kidney transplants may include some with pancreas transplant but we do not have separate data for kidney-pancreas recipients. Their risk would be expected to be the same as kidney recipients.

Is there any data for hearts, lungs and livers?
Risk of serious COVID-19 infection is similar for non-kidney organ transplants to kidney transplants, however lung recipients have a higher risk of serious COVID-19 disease.

I've read that the vaccines are presumed safe for pregnant women – what is the recommendation for TX patients who are of child bearing age (looking to undergo IVF procedures)?
Neither Pfizer nor AstraZeneca vaccines have shown any adverse effects to the foetus in the small number of women who have become pregnant in the vaccine studies, and animal data does not suggest any adverse effects of vaccination on the foetus. The government stance is that pregnant women can consider being vaccinated if they have factors to increase the chance of severe COVID in pregnancy (and having a transplant is one of these). At the moment, the Pfizer vaccine has a little more data in pregnant women and is likely to be preferred if you are actually pregnant, but if you are simply contemplating pregnancy either vaccine is fine.

Will parents and carers of under 16 transplant patients be eligible for the vaccine before the general public, considering that the child can't get it until they turn 16?
Because children (even immunosuppressed children) have low rates of serious COVID-19 infection, contacts of immunosuppressed children are not planned to move up the queue at the moment.

If you donate your kidney to a living relative then should I be vaccinated?
Donating a kidney does not make you unhealthy, so you would be considered like the general population who are all being encouraged to be vaccinated. We suggest you should be vaccinated.

Will the vaccine be as effective for those who have recently had a kidney transplant - less than 6 months, higher dose of pred and other immunosuppressive meds?
The immunosuppression is at the highest level initially after transplant when vaccine response may not be quite as good, so we will likely suggest waiting about 3 months after transplant to get vaccinated. Formal advice should be out soon.

I have had a kidney transplant and am looking forward to getting the jab. However my partner wants to know, can he get a jab at the same time? If he doesn't, won't that keep me at risk?
The priority is to protect you and If you get the vaccine that will help protect you, and the added protection of vaccination of your close contacts will occur later.

Does vaccination increase antibodies in the event you need another transplant in the future(god forbid). this would be general to vaccine not just the covid?
The antibodies produced from the vaccine are specific against COVID and not against organs, so we do not expect these antibodies to cause problems with organ rejection, and our experience with other vaccines suggests they are safe in this regard.

Can we get multiple vaccines, will that improve the odds or is more than one too many?
Individuals are likely to require more vaccine doses and perhaps different types of vaccines as time goes on, but we are not sure about this yet. Vaccines have not been mixed with each other in any trials, so you only get the one type for now.

Since Australia has such low COVID cases, should immunosuppressed patients wait until there is more data on the vaccines before getting it?
The future is uncertain, and one prediction is that travel will open up and borders become more lax with vaccination across the world, with more likelihood of circulating COVID-19 infection in Australia. The vaccines are not live so also do not expect them to cause significant adverse effects in transplant patients. So we don't think you should delay getting vaccinated.

Will my 16 year old daughter with KT be in group 1b or group 5?
Age 16 or over is the approval for the Pfizer vaccine, so we would think phase 1b.

What is the time line for getting the vaccination post transplant?
The guidance is yet to be formalised, but we are likely to suggest you wait about three months after transplant before being vaccinated to get a better response to the vaccine.

Will immediate family members get opportunity to get vaccine at same time as transplant patient?
No, the vaccine is distributed based on where individuals come in the phases.

Are there any details on COVID vaccinations affects on Kidney TX patients who are currently being monitored for viruses such as the BK virus?
BK virus infection and disease should not impact the vaccination at all.

Why are the rates of death from COVID-19 higher in dialysis patients?
We are not exactly sure.

Is there any data to say if the vaccine effects fertility?
There are no signs that the vaccines affect fertility.

Will the systemic reaction after the vaccine be proportionate to the antibody response (and efficacy)? Is there any evidence so far?
Yes there probably is an association of local or systemic reactions to vaccine response but this hasn't been described so far.

Am on dialysis take Claxane. Can I have the vaccine?
Yes you can have the vaccine on anticoagulants. You will need advice from your doctor about management of the clexane at the time of vaccination.

What about those in rural and remote areas. Will it take us longer to get a vaccine?
No. Vaccine hubs are being set up in rural areas.

Any concerns for HTx patients with PTLD?
Not specifically. But you will need to speak to your doctor about this situation as you may have had rituximab which does lower vaccine responses for some months after the drug.

I had my transplant three months ago but have another condition that flared up a month after transplant Familial Mediterranean Fever, so how will the vaccine effect my case?
The vaccine is not expected to cause exacerbations of inflammatory conditions such as Familial Mediterranean Fever. We would advise you to be vaccinated.

Is it safe to get covid immunisation if patient had allergic reaction with flu?
Yes. The only reason you can't get a COVID vaccine is severe allergy to the COVID vaccine itself. If you had severe reaction (anaphylaxis) to another vaccine or drug, sting, food, you will be monitored for 30 mins rather than 15 mins after the vaccine as a measure of caution.

If you are working from home would you advise to continue to do so until you are vaccinated?
It depends on how much COVID is circulating in the community. If COVID is not circulating in your area, it should be safe to be at work.

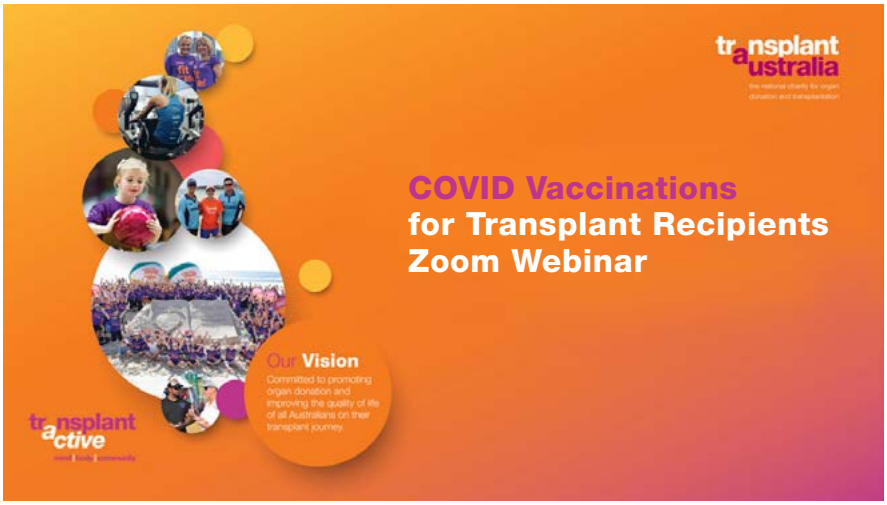
I am interested to know if there is a difference in the efficiency of the vaccines with the differing immunosuppressant drugs? The research you referred to mentioned some of the most common types of immunosuppressant drugs?
We are not sure of this at the moment, but from research with other vaccines we know that certain immunosuppressants can affect response to vaccine more than others, but the main drugs which do this are generally given only early after transplant, or sometimes as treatment for rejection.

What group will pre transplant patients will be in for the vaccine?
Phase 1b because they all have organ failure.

Given there is quite a discrepancy in the efficacy of vaccines will the medical transplant community have a say in which the government give us?
Immunisation experts continue to guide the government on the best vaccine for each particular group of society based on what is available, what the evidence shows, and what is most optimal for each group of individuals.

You can access further questions and answers on the transplant australia website below...

As an immune suppressed person, post heart transplant in 2019, I had my first Pfizer vaccination recently and experienced only a slightly tender injection site. Talk to your medical team about your circumstances and listen to only official sources of information. *EDITOR*



https://transplant.org.au/living-with-your-transplant/self-care/covid-19-and-transplant-recipients/

The match-makers

Facilitating organ transplantation takes a village; an entire team working together across the nation to give someone a chance at life.

Part of this vital team is the Victorian Transplantation and Immunogenetics Service (VTIS), at Australian Red Cross Lifeblood.

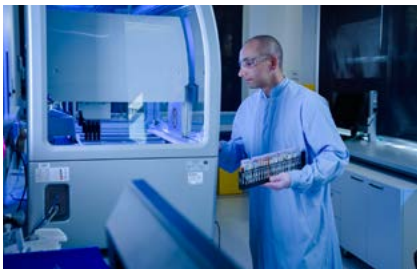
This team are the *'match-makers',* who within around 8-10 hours uncover which patients on the waiting list are potentially suitable to receive a precious organ.

Explaining this process is Rhonda Holdsworth, Director Transplantation and Immunogenetics Services.

"Our team is on call 24/7 to receive samples from a potential donor to see if we can find a match," Ms Holdsworth said.

"This 8-10 hour long process involves extracting DNA from the donor samples, getting it into a useable form, thawing

Blood and plasma donors must be between 18 and 75 years of age, and feeling fit and well in order to donate. To book, people are encouraged to call 13 14 95, download the Donate Blood app or visit lifeblood.com.au



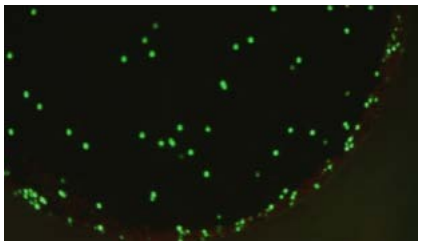
serum samples from patients on the waiting lists, then performing lab tests to determine compatibility,

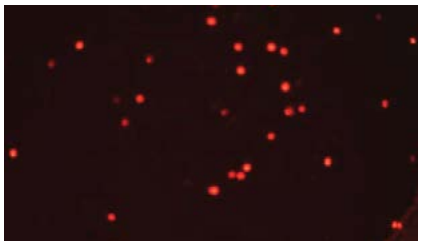
"Samples from both the donor and patient are then put together to test whether it's a good or a bad match.

"In the simplest terms, it's essentially like doing a virtual transplant – putting the two samples together. This process allows us to test for reactions without putting a patient at risk.

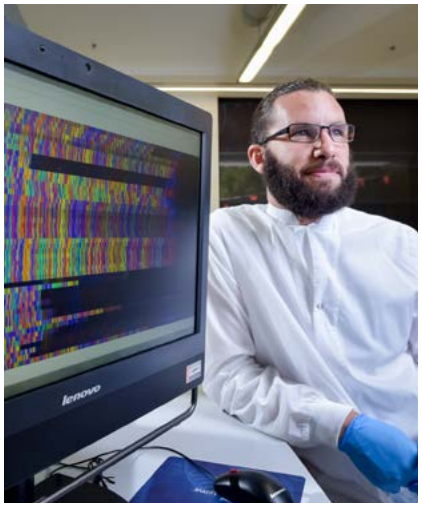
"It's not so much about finding a perfect match, rather, avoiding bad matches.

We can see this reaction through the microscope where a fluorescent stain shows up either green (good) or orange (bad).





"Each patient is then given a score according to the strength of their reaction – this scoring system is like golf, the patient with the lowest score has the best chance of success with their transplant.



"Once this process is completed all the results from this and other tests also taking place, are cross-checked before being sent back to hospitals."

Lifeblood's role doesn't stop there with blood and blood products often required during some transplants, including heart and lung transplants.

Lifeblood spokesperson Erin Lagoudakis talked about the ongoing need for blood.

"We need 31,000 donations every week to meet patient needs, and a blood donation is needed every 24 seconds," Ms Lagoudakis said.

"One in three Australians is likely to need blood or a blood product at some point in their life, yet only one in 30 donates.

"While those who have received solid organ transplants are unable to donate, encouraging friends or family to donate blood or plasma on your behalf will continue to help patients in need."

Australian Red Cross Lifeblood

Blood types and doughnuts

What are blood types and why do they matter?

Australian Red Cross Lifeblood

What's your type?

Blood type, I mean. You may already know that you're an "O negative" or a chirpy "B positive." Or one of many other combinations of A, B, O positive and negative. But what do those letters mean, why do they matter, and what does the future of blood typing hold?

I know my type – I'm O negative-which means I'm a universal blood donor-and similar to about 8 percent of the population of Australia. What does that actually mean?

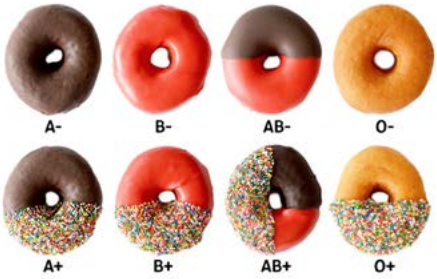
Imagine for a moment you're taking one of those Magic School Bus dives into a blood stream. You shrink down to until you're as tall as about 1/10th the width of a human hair, and you are swept along through the blood vessels with the red blood cells that are carrying oxygen to your cells. You shrink down even further, until you are able stand on one of those cells as if you were using it as a surfboard. When you look down, you can see the individual proteins that make up the surface of the red blood cell. These proteins are like signposts, machines, gateways and scaffolding, helping the red cells maintain their saucer-like structure and do their job.

Some of these proteins are responsible for your blood type. Like all the proteins that your body makes, the ones that decide your blood type come from genes that you inherit from your parents. These particular proteins are called antigens.

Antigens are so-named because they can stimulate the body to make antibodies – so they are ANTIbody GENerating. If your body sees unfamiliar antigens in your blood, your immune system will recognise them as invaders them and try to destroy them.

When we talk about blood types, "A" and "B" refer to two specific antigens on the surface of your red blood cells. These letters technically describe carbohydrate "decorations" on a protein molecule. And because carbohydrates are sugars, we can use sugar decorations to demonstrate the point. Imagine a blood cell as a doughnut.

People who have the A antigen on the outside of their red cells are type A (think of A as chocolate icing on your blood-cell doughnut).



People who have the B antigen on the outside of their cells are type B (think of B as strawberry icing on your blood cell doughnut).

People who have blood type O don't have either type of decoration (think of an un-iced, classic doughnut).

So what about the positive and negative?

That's another antigen, called the "Rhesus" or "D" antigen, that is completely separate from A, B and O.

Generally, people either have the D antigen (in which case they are "positive") or they don't (in which case they are "negative"). I like to visualise this as sprinkles on the icing of the doughnuts. Like this:

Why do we worry so much about blood types?

It's because of those antibodies we mentioned before. If you are blood type A, you will develop antibodies to the B antigen and vice versa. If someone has antibodies against a blood group antigen, and they have a transfusion that contains that antigen, the antibodies will attack and destroy the foreign red blood cells. This is not only a waste of a good blood transfusion, but the broken blood cells can overload the kidneys with iron, which can be fatal.

So now we know that matching blood types is important, and we can see why the "O negative" plain doughnut is the universal donor (there are few antigens on the surface to provoke a response), and why people with AB positive blood type can take pretty much any blood type (they are used to all the trimmings).

But it gets a bit more complicated. The ABO and rhesus blood group antigens are just the most "clinically significant" antigens, which means they are most likely to generate destructive antibodies, and therefore are super important to match in any transfusion. Apart from these, though, there are literally hundreds of different blood group antigens across 36 blood group systems. *(Each system is a molecule on a red blood cell's surface that may contain one or more antigens.)*

If I needed a transfusion, since I'm O negative, you could find an ABO match for me in about in about 8% of the population in Australia. If you needed to match all the antigens in my blood, it would be much more difficult (closer to 1 in 10,000).

Going back to our doughnut analogy, the full picture of antigens on red cells look more like this:

Obtaining a perfect match between donor and patient isn't always necessary, but for people who need regular transfusions, it's important to match as many blood groups as we can. If we don't, they may develop antibodies that make it harder and harder to find compatible blood as their treatment continues. For example, people with thalassemia and sickle cell anemia sometimes need many transfusions every year, for life.

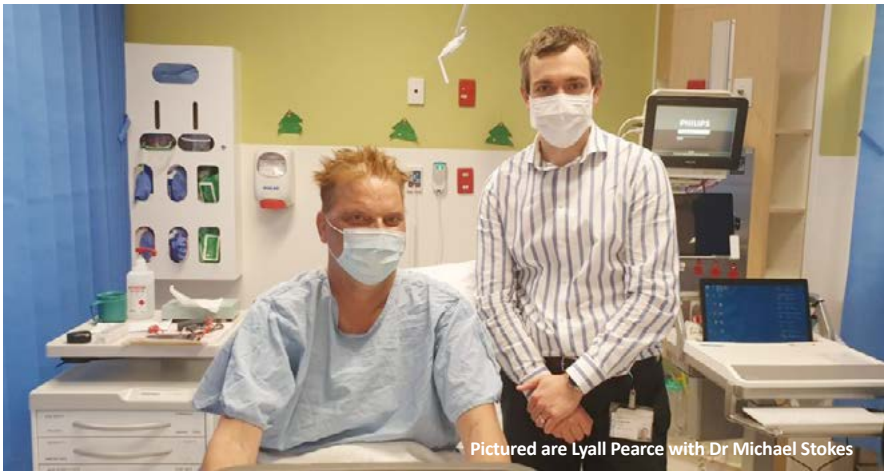
Traditionally blood typing is done using antibodies. A pathologist takes a patient's blood sample and mixes it with an antibody against a certain antigen, which means one antigen can be checked per test. You can imagine it can be very time consuming to do a full blood group test. But because blood groups are determined by your genes, we can now use genetic testing to determine many blood groups at once, which can help us solve cases where no test exists.

At the Australian Red Cross Lifeblood, one of our research groups is using the latest genetic techniques, including massively parallel sequencing, to characterise new blood group antigens. They have found a number of new blood group antigens in the last few years, and are working hard to improve our ability to quickly and accurately match blood types for all patients.

Dr Alison Gould MRACI CChem
Scientific Communications Specialist
Member of the Australia Science Communicators

Miracle patient's survival thanks to Australian-firsts

The heart and lung transplant community in Australia is shaped by a strong willingness to embrace innovation and technology when it is supported by science and research. Lyall Pearce is one beneficiary of that.



Pictured are Lyall Pearce with Dr Michael Stokes

Lyall Pearce was feeling fit and healthy, having just celebrated his 50th birthday.

"My grandmother lived to 101, so I was thinking I had about another 50 years left," the husband and father of two from Hillcrest said.

But when the ride to work he did every day suddenly became a struggle, he felt something was wrong.

"I used to ride my bike every day to work about 9-10km, rain or shine. I found it started to get more and more difficult to get up a hill along the way."

Prognosis

After seeing his GP and being referred to a thyroid specialist, he was finally diagnosed with Multiple Myeloma with secondary cardiac amyloidosis (due to the toxic protein produced by the myeloma cells), and given an 18 month prognosis.

That was in 2015.

Lyall's journey

Although Lyall had numerous hospital admissions and side-effects, he initially responded well to chemotherapy under the care of by haematologist Dr Noemi Horvath.

But the impact of the chemotherapy treatment and the infiltration from the amyloidosis in his heart had severely impaired his heart's function.

Doctors installed a pacemaker and he began heart medications, but by mid 2020 his situation was dire and had developed resistant heart failure despite numerous medical interventions.

Lyall was essentially bed-bound and unable to move without becoming breathless and his other body organs had started to be compromised due to his extremely poor heart function.

During an admission to the Royal Adelaide Hospital in June 2020, Lyall was flown urgently to St Vincent's Hospital in Sydney where he waited for a heart transplant.

As his clinical status deteriorated, to bridge him during this wait, the team at St Vincent's Hospital installed a specialised mechanical cardiac device called an Impella Device.

An Australian first

"He is the first person in Australia to have a short-term Impella pump implanted while supporting him to an urgent heart transplant," CALHN cardiologist Dr Michael Stokes explained.

"Some patients may have much longer periods of mechanical cardiac support with a ventricular assist device (LVAD), but this wasn't a viable option for Lyall.

"The Impella is used very rarely, usually in patients recovering from a large heart attack for a few days. It's only been used a very small number of times in Australia."

Four days later on July 1, Lyall had a heart organ donor match, and he was one of the first myeloma-related amyloidosis heart transplants performed in Australia.

"Lyall has taken part in a number of clinical trials and he was able to get compassionate access to an anti-plasma cell antibody (called Daratumumab) that has shown promising results in myeloma patients," Dr Horvarth said.

"This was successful in keeping Lyall's toxic protein production under control for 18 months.

"In spite of that, his heart function continued to deteriorate so it was fortunate that he was eligible for the subsequent treatment he received."

Lyall spent several weeks in ICU and then on the ward at St Vincent's Hospital, but is now back home recovering and relatively independent.

Looking forward

"We think he is going really well and we are optimistic," Dr Stokes said.

"He's five months post-transplant and requires long-term immunosuppressive therapy."

While still battling amyloidosis, Lyall has new goals to achieve.

"It's just a matter of being able to get my fitness back. I'd like to get on my bike again."

He is also hoping to get back to work next year at DXC Applications where he has worked as a support specialist for 20 years.

Story courtesy Central Adelaide Local Health Network, a part of SA Health, 2020

As this edition goes to print, Lyall has just returned to Adelaide after undergoing an autologous stem cell transplant at St Vincent's Hospital to assist in his journey to overcome amyloidosis.

Read more about this extraordinary story of persistence and survival on page 13...

Government of South Australia | Health Central Adelaide Local Health Network

Leave no stone unturned...

What value do you place on a human life? The answer to that is unique to every person, but many people ably demonstrate their response by the lengths to which they will go to save a love one.

I met Lyall and Veronica last year and couldn't help but be inspired by the sense of purpose and sheer doggedness and determination they both displayed in their shared goal of finding a solution to Lyall's medical challenges. This story by Veronica, although not an 'Alfred' one, will resonate with everyone who has been on the heart and lung transplant journey because most of us have experienced complications and unexpected challenges we've had to navigate around. Editor

Everybody's journey is unique, everyone reacts to medications and treatment procedures differently.

This story is about my brother's journey with Cardiac (AL) Amyloidosis through my eyes as one of his closest advocates.

I share this story in hope that it may help others; especially if you are like me and are wanting to help and support your sick loved ones too. The bottom line is never give-up, there is always hope.

My name is Veronica Pearce and I've been living in the USA as an expat Australian since 1999.

In October 2015 I was on a morning walk in San Antonio (Texas), when I received a phone call from my brother Lyall Pearce who was living in Adelaide, Australia. He told me his medical test results were back and his doctors suspected he had some form of Myeloma that was adversely affecting his heart.

I stopped walking and sat down on the side of the road. He explained it as a blood/bone cancer and said they had a few more tests to perform and we would know more within the few days.

Lyall recovering after his heart transplant. 2020

Sure enough, several days later Lyall's formal diagnosis came back as Cardiac (AL) Amyloidosis which is a complication of Myeloma. I couldn't even pronounce these words, let-alone understand what they meant.

After some research online I learnt myeloma is a form of bone marrow cancer where the plasma cells (produced from the bone marrow) are faulty. In Lyall's case, these faulty cells produce antibodies that misfold into a plaque-like protein (amyloid) that gradually deposit in the heart tissue, slowly thickening his heart walls, adversely affecting his heart – hence the diagnosis of Cardiac (AL) Amyloidosis.

In the year prior to his diagnosis Lyall knew something was medically wrong, his cardiac fitness was deteriorating quickly and significantly, he was finding it harder and harder each day to ride up hills on his normal 20km round trip daily cycle to and from work.

At the time he was diagnosed (October 2015), his prognosis was terminal, and he was given 18 months to live.

It was a windy road we took

Despite a poor prognosis, Lyall's medical team established that the best way forward was a treatment regime of firstly chemotherapy, shortly followed with a stem cell transplant to remove the faulty plasma cells in hope to extend his life.

In the days and weeks following Lyall's diagnosis we had so many questions. It was totally overwhelming. The best thing I did at that time was self-education: reading hospital issued brochures, literature from the Leukaemia Foundation, online research, forums, and lots of questions to doctors, staff at the Foundations, other patients we met in waiting rooms and anyone else who could offer any insights and guidance.

Initially, I couldn't understand much of the documentation, all the medical terms

and complexity of it all was like trying to read something in a foreign language. But as I gradually learnt what the terms meant (Google Search became my best friend) things started to make a little bit more sense.

We learnt there were some critical parameters we needed to start following to monitor Lyall's health – just like someone with diabetes who closely monitors their blood sugar levels and take corrective action when its low or high.

For Lyall's Cardiac Amyloidosis the main parameters were initially: Lambda Free Light Chains (FLCs), Troponin, NT-ProBNP, temperature, blood pressure, heart rate and weight. Once we understood these critical parameters were indicative of Lyall's future health, we took responsibility to track them and proactively took quick action and/or asked for advice/help from his medical team when it was clear something was trending off-track.

I just want to re-iterate this, because it is important, if a health parameter is going off-track, or a new symptom develops, don't wait to see what happens, act FAST and ask for advice immediately. If something really is wrong, there is a much better chance of recovery if it is identified and treated early.

In October 2015, Lyall started his first chemotherapy regime with *Velcade* administered by intravenous infusion, and continued through to late December 2015. The regime was successful at reducing his FLCs down from 65mg/L to 32mg/L (normal is between 5.7 - 26mg/L). His levels weren't quite within normal range yet, but they were at least heading in the right direction, so in early January they proceeded to collect his stem cells in preparation for his stem cell transplant which was scheduled for later that same month.

However, by late January 2016, and despite lowered FLCs, his heart parameters were still deteriorating and his cardiac health was deemed too poor for him to survive a stem cell transplant procedure, so it was cancelled.

The only way forward was to pursue further chemo treatments and hope his heart health would improve at which time they would reconsider proceeding with the stem cell transplant.

During a month break from chemo it was hoped the *Velcade* regime would continue to reduce his FLC levels, or at least hold them steady for a while, but unfortunately his FLCs shot back up to 64mg/L – well above normal. Given this regime did not 'hold', and the heart parameters were not improving, a different regime of *Melphalan* would be administered to see if it would work any better.

Another seven weeks after replacing *Melphalan* back to *Velcade,* his FLCs were still not dropping so intravenous infusions of *Thalidamide* were added to the *Velcade* regime.

By late March 2016 tingles in the feet and hands started developing along with dizzy spells and puffy skin from fluid retention in the body (oedema) – typical for patients with heart-failure.

In early April 2016 his FLCs had successfully reduced to 23mg/L, within normal range. We continued with this chemo regime though to the end June 2016. However, his heart parameters (Troponin & NT-ProBNP) were not improving making a stem cell transplant further and further out of reach. We needed to find a treatment that would not only help control his blood cancer but would help his heart too.

Getting a chemo infusion. 2015

Given Lyall's condition crossed two disciplines of medicine, hematology for the bone/blood cancer, and cardiology for heart failure, it was becoming a delicate juggle on how to treat and medicate both. There weren't any regimes on the PBS list to help remove or reduce deposited amyloids from the blood or heart Lyall's options for treatment were becoming limited.

We asked about the possibility of a heart transplant in the future should his heart continue to deteriorate, but were told, at this time, it was not an option as treatment with traditional chemotherapy was an 'Exclusion Criteria' for heart transplant patients – most chemotherapy medications interfere with the immunosuppressant medications used to prevent organ rejection after transplants.

Further, Lyall's blood cancer would probably eventually infiltrate and damage the new heart too. So, for Lyall's condition, based on the treatments available at the time, this was not an option. It made sense, we understood why, and at that time as hard as it was we accepted it, but it was truly devastating trying to accept the finality of it all.

Despite Lyall's poor prognosis, we knew the technological developments in this medical field were moving fast – so there was still hope and the need to refocus on the hope, push-on and keep exploring options.

In mid-April 2016 some online research uncovered a promising clinical trial report about the use of antibiotics, specifically *Doxycycline,* where it disrupted amyloid production by preventing fibril (amyloid) formation. We asked his medical team about it and they agreed it was worth a try, so Lyall started taking *Doxycycline* too in addition to his chemo regime.

In May 2016 Lyall had a set-back, he presented to Emergency with an elevated temperature and feeling weak. The big lesson for us here, we waited too long to seek medical attention when a key parameter went off-track. He was admitted to ICU with Viral Pneumonia.

During May and June his heart parameters deteriorated significantly. His NT-ProBNP skyrocketed reaching over 17,000 ng/L (normal is less than 900 ng/L). Lyall's heart ejection fraction (EF) dropped to 32%, meaning only 32% of the total amount of blood in his heart's left ventricle was being pushed out with each heartbeat (normal is greater than 55%). However, to our surprise his Troponin levels dropped back into the normal range, and his FLC levels dropped significantly down to 6mg/L, on the low-end of normal scale, which meant chemo could be stopped for a little while – a break his body really needed.

By this time, end of June 2016, Lyall's tingly fingers and feet had developed into full numbness of limbs below the knees and numbness in the hands, including loss of ability to feel the difference between hot and cold. His dizzy spells had developed into regular and problematic blackouts with his baseline blood pressure now consistently dangerously low.

He was diagnosed with both peripheral and autonomic neuropathy, the latter causing postural hypotension, which is when the body becomes unable to self-regulate blood pressure so when he stood up from a lying-down or seated position, his blood pressure couldn't auto-correct quickly enough to sustain adequate blood to the brain causing him

to black out and collapse. Fortunately, they could medicate to help raise his baseline blood pressure to help reduce the blackouts, but there was nothing they could do to help with the numbness in the limbs. *Velcade* and *Thalidamide* could no longer be used for chemo due to these adverse side-effects so we had to find another treatment.

While he was on a break from chemo we took stock of our options, I knuckled down and did more research. I called almost all the Amyloidosis Centres throughout Australia and the USA, including the Stanford Amyloid Center and Mayo Amyloid Clinic in Minnesota, asking for educational literature and advice. I read abstracts and papers from both clinical trials and medical conventions specialising in Amyloidosis treatments and future developments.

The most promising treatment found from this research was *daratumumab (Darzalex),* it was the first monoclonal antibody approved for use in multiple myeloma, and a small clinical trial in the USA showed really good results for Cardiac (AL) Amyloidosis patients.

Lyall's medical team advised they had been monitoring the development of this new treatment, but unfortunately, *daratumumab* was only available in the USA and not in Australia yet. We needed to find something else in short term.

Travelling to the USA for treatment with *daratumumab* was cost prohibitive and most likely a poor quality-of-life choice with Lyall separated from family and friends.

Our remaining choices within Australia were to limited but we found a clinical trial for a new promising monoclonal antibody treatment called PRONTO NEOD001. It was specifically for treatment of Cardiac (AL) Amyloidosis. Preliminary results showed it had potential to stop formation and even remove amyloid deposits from the blood and heart. The medical team agreed to help us pursue this clinical trial and helped us work through the process.

Over the next few months Lyall's FLC's were fortunately holding firm in the normal range, so the pressure was off to find another quick chemotherapy solution. Instead, this gave his medical team time to get things set up for the NEOD001 Trial which was being managed in Melbourne. It took many months of paperwork, interviews and preliminary medical tests to qualify for the clinical trial and much time and effort invested by both his Adelaide medical team and the clinical trial team in Melbourne to co-ordinate everything.

While we waited for the approvals to participate in the PRONTO Clinical Trial, we continued our research, and we found another medication called *EGCG.* It showed promising preliminary clinical trial results to help remove amyloid deposits. Given *EGCG* was readily available, we asked his medical team if we could try it while we waited to get approvals back from the PRONTO team. Although they were against it and erring on the edge of saying 'no', they finally relented and agreed to let us try it as an interim treatment. (In hindsight, they were right, the *EGCG* regime did not help Lyall's condition at all).

After much waiting, in early January 2017 Lyall was invited to travel to Melbourne by the PRONTO NEOD001 team for his final interview and medical tests, the last step to quality for the clinical trial. We were excited. Reports were showing good preliminary results and it was wonderful to have hope again. Lyall's FLC levels had crept up over the last few months and were bordering the top end of the normal range, so it was perfect timing for the PRONTO NEOD001 regime to commence. But we returned from Melbourne without qualifying for the trial due to a silly mix-up on our end.

We were told Lyall was to stop taking ALL medications for 6 weeks prior to this interview, but we interpreted it as to stop taking chemotherapy. Although Lyall had been chemotherapy free for months, he had still been taking *EGCG* and *Doxycycline,* which disqualified him. This was a BIG lesson for us; to make sure we clearly cross-matched medications, one-by-one, with his medical team regularly to ensure we were using the right medications and doses.

Although Lyall missed out this time, he was invited to qualify in a further six weeks time if the last spot in the clinical trial had not been filled by someone else.

In mid-February he travelled back to Melbourne again, this time he qualified and was approved to participate in the Trial. Two weeks later (early March 2017) he was given his first infusion which had a 50/50 chance of being either NEOD001 or a Placebo. It was a randomised, double-blind trial, so we would never know if he was being given NEOD001 or the Placebo. Risky, yes, but with virtually no other options offering real hope, it was worth the risk at that time.

Ever since Lyall was diagnosed, to keep ourselves up to date on the medical industry developments to treat Lyall's condition, we signed up to receive email updates, newsletters and media alerts from various organisations, institutions, foundations and medical manufacturers who specialised in Amyloidosis. These updates were particularly useful.

In July 2017 we received an email alert advising us that *daratumumab* had now been approved for use in Australia based on 'Compassionate Access' only (but it was still not on the PBS). At the time, Lyall's FLC's and amyloid deposits were not showing any signs of improvement from four months of treatment on the NEOD001 trial, so this alert on *daratumumab* was a new sign of hope.

We immediately reached out to his medical team, stating we still wanted to pursue *daratumumab* as a high priority, and asked what needed to happen next to get the ball rolling. His team reported they were aware of the announcement and they had already commenced correspondence with the manufacturer and discussions were in progress, but it would take time.

By mid-September 2017 Lyall was still deteriorating, and his FLC levels were still increasing at a steady rate and were now well above normal. He opted to abandon the PRONTO NEOD001 clinical trial and as a stopgap he recommenced *Doxycycline* and *EGCG* until another chemo regime could commence.

Looking at the remaining chemo regimes that were left for Lyall to try on the Australian PBS list, it was quite disheartening as they were all derivates of treatments he had tried in the past which were risky due to adverse side-affects, or they were derivatives of treatments that had not worked.

In desperation, knowing *daratumumab* was now in Australia, and it was not clear the status of getting Lyall access to it, I reached out for help to the medical manufacturer directly, the hospital, various local, state and national health ministers. I let his medical team know my actions and they promised they were still vigorously pursuing access to *daratumumab,* and it would still be a long road ahead before we could get it, but the wheels were slowly turning. We just needed to wait and hope we could get it before it was too late. We had to find something else in the meantime.

In early October 2017 Lyall stopped *EGCG* and started a new low-dose regime of chemo called *Lenalidomide (Revlimid).* The new regime was one of very few left on the PBS, all of which were undesirable based on Lyall's medical history. Fortunately, it successfully lowered Lyall's free light chains down to normal levels within a couple of weeks and his side-affects were minimal.

In November 2017 chemo was intentionally paused to see if these low FLC levels would 'hold'. Unfortunately

they didn't. This was incredibly upsetting as this meant *Revlimid* was not going to be sustainable for Lyall for very long. *Revlimid* was re-started at half the low-dose in hope it would buy us more time, and it was back to the drawing board to determine what regime to try next. In the background, his medical team continued to pursue getting access to *daratumumab.*

By December 2017 Lyall's FLCs had slowly crept up to above normal levels again and by June 2018 it was clear they were going to continue rising. Half the low-dose *Revlimid* was no longer sustainable and an increase in dose was too risky due to adverse side-effects. In June 2018 Lyall took his last dose of the *Revlimid* chemo regime.

In mid-July 2018 to our complete surprise, Lyall's medical team announced they had finally secured special access to *daratumumab (Darzalex)* and that same week he had his first infusion. Within three weeks his FLC levels dropped back to normal. Lyall has been on *daratumumab* ever since (it's now February 2021 as I write this article) and his FLCs have been maintained at normal levels with no other adverse side-effects. He also continues to take *Doxycycline.*

Back to late 2018, although on a Haematological basis Lyall's FLCs were now being maintained at normal levels using *daratumumab,* and by definition in medical terms he was (and still is) considered to be in 'remission', but it was still the view of his medical team he still had cancer and treatment needed to continue.

Even though Lyall's FLCs levels had been stabilized, his heart was now too severely, and irreversibly damaged and Congestive Heart Failure was still progressing. In late 2018 we needed to shift gears and move our focus from the Hematology discipline and start focusing heavily on the Cardiology side of things.

Back to research, asking lots of questions and more self-education. There were so many different heart devices and aids that can be used to assist cardiac patients. Lyall's medical team helped us understand all the options available to Lyall to potentially improve his heart condition and in February 2019 Lyall had heart surgery to have a bi-ventricular device installed.

By December 2019 Lyall was still stabilized on a haematological front with normal FLC levels, but his heart condition was still deteriorating with his Ejection Fraction (EF) getting worse. His fluid retention (oedema) becoming almost unmanageable at home, requiring frequent in-patient hospital care and he was experiencing constant low blood pressure and blackouts were becoming more and more frequent. Again, we started asking his medical team for possible options moving forward.

The biggest question we asked was associated to a heart transplant. We knew that Lyall was previously excluded from a heart transplant because his chemotherapy medications would interfere with the immunosuppressant medications used to prevent organ rejection after the transplant. But Lyall was no longer on chemotherapy medications, instead he was now on a new monoclonal antibody regime *(daratumumab).* Would the monoclonal antibody interfere with the transplant immunosuppressant medications too? If not, would that open the door for Lyall to now be considered for a heart transplant?

Additionally, knowing that his FLCs have been maintained at normal levels now for a significant time (1.5 years), medical remission, would this also change things with regards to qualifying for a heart transplant?

In early 2020 Lyall was approached by his medical team with an offer to participate in a clinical trial for *"Orthotopic heart transplantation followed by autologous stem cell transplantation in patients with cardiac AL amyloidosis - a Phase II study".*

Words cannot explain our relief – once again there was renewed hope. Over a period of about two months, all the preliminary medical tests were done to determine whether he would qualify for the *Heart Transplant & Stem Cell Transplant (HT/SC) Clinical Trial.* Many medical tests later and several trips to Sydney for interviews, he was told he qualified. We were advised he was now added to the Heart Transplant waitlist. What an incredible turn of events.

By May-June 2020 Lyall's hospital visits became so frequent due to unmanageable fluid retention and blackouts that he was spending more time in hospital than at home. By mid-June he was deemed to have an unmanageable cardiac condition by

Having experienced both the medical systems in the USA and Australia, I need to take a moment to say how grateful I am for the public system we have in Australia. The Australian public health system is so much more streamlined with different functions often managed under the same entity (a hospital) using a centralized system, resulting in healthcare being relatively cost effective to the end user.

The USA system is very divided, with different functions in their hospitals often managed as many separate smaller corporate entities which typically use their own systems, equipment and software, creating complex webs of non-centralized documentation, dataflow and financial management. As these separate entities use each other's services, they compound their workload and put a further financial drain on the overall health system by invoicing each other, creating the additional requirement for more staff and resources to manage it all.

Further, because these USA entities run independently of each other, they are each legally at risk from lawsuits and need to buy their own insurance policies which are often awfully expensive. With the USA Insurance industry still mostly operating under a brokerage system, there is another financial draw for commissions to support brokerage firms.

Comparatively in Australia, a public hospital being managed as several large entities instead of 1000's of smaller ones, the overall funds required to cover expensive insurance policies is exponentially less. Many insurance policies are negotiated directly with the insurance provider instead of through a broker, so the additional expense to support broker commissions is also significantly reduced. With all the additional resources required to support the service segregated health system in the USA, the costs involved to operate their complex system are massive.

With respect to funding healthcare, in Australia's favour, the Government collects a Medicare Levy from all taxpayers which is used to help offset the cost of healthcare via Medicare making it affordable and accessible to all Australians.

In the USA, a levy like this does not exist. Obamacare (USA Patient Protection and Affordable Care Act of 2010) was in part an attempt to mandate something similar, but this mandate didn't hold and was in recent years lifted. As a result, the burden of healthcare often falls on the individual or their health insurance provider. With health insurance being extremely expensive, its not affordable to many, leaving many Americans without health insurance and the heartbreaking choice to not seek medical care when they need it because they can't afford it.

Here in Australia, we often take many things for granted – unfortunately the Australian Public Healthcare System is one of them. **Veronica Pearce**

After the Impella surgery. 2020

the Royal Adelaide Hospital, and he was flown from Adelaide to Sydney on a medivac flight for more specialised treatment at St Vincent's which, along with The Alfred in Melbourne, is a major Cardiac Medical Services and Care hospital.

At the end of June 2020, Lyall's heart could no longer pump enough blood through his body to sustain him and some of his other organs started to fail. With his heart being abnormally shaped and with very thick walls, traditional cardiac aids to improve his condition would require novel surgery and was deemed too risky.

Instead, Lyall became the first person in Australia to have a tiny temporary pump, called an Impella, installed inside his heart to help boost his blood flow to keep him alive while he continued to wait for a donor heart. The lifesaving Impella surgery sustained Lyall for four days until he received a Heart Transplant on 1 July 2020.

Once we were advised a donor heart had become available, everything happened so fast. The emotions were overwhelming; gratitude, relief and joy this day had finally come, fear and worry of what could go wrong and the unknown, grief and sadness knowing another family's lives had tragically changed forever.

The heart transplant surgery itself took only 5 hours and his recovery over the next week was incredible to watch and much faster than I ever imagined.

But then into the second week of recovery we had a major set-back, he started to feel off-colour, brain fog and confusion, difficulty with hand motor-skills (dropping things), balance, weak, affected vision (he saw sparkly little worms in the clouds) and he had a few unusual heart-beat events. A few days later he collapsed.

His medical team acted incredibly fast and he was in open heart surgery within minutes to fix the problem. He had suffered an internal bleed in his chest cavity which caused a Cardiac Tamponade event; where the blood filled his chest cavity, pressurised it, and the pressure caused his new heart to fail.

His recovery started over and again. He was conscious within 24 hours of the second surgery. But this time, something was slightly different, his speech was slow, somewhat simple and disjointed. He would snap out of it and speak normally, then he would revert back and speak slow again. I didn't think anything of it at first and put it down to 'recovery', but after a quick consultation with family we felt it critical to let the medical team know in case he'd had a TIA (mini stroke). They acted immediately and he went through many tests. They all came back clear, no evidence of a stroke.

But his behaviour was still not normal, and it was getting worse. Confusion, speech, vision, hearing, motor-skills were all being affected in waves. For one hour he would be ok, then for 1-2 hours he'd fall into a state where he could not function and he was reporting that he was in pain. Then he would snap out of it and be normal, no pain.

The cycle continued and the episodes became longer and worse. Specialists were quickly brought in from many disciplines throughout the hospital to assess and run tests to rule out various potentially debilitating diseases, viruses, and disorders. All tests came back clear.

It was during this time, when he had lost his ability to effectively communicate, where I felt I was advocating for him the most. Knowing Lyall's normal behaviour, it was easy for me to see when there was improvement, deterioration, change and/or new symptoms.

Often, I would see changes quickly and could raise the red flag early. His nurses and carers couldn't to do this because they didn't know Lyall and couldn't differentiate normal behaviour from abnormal.

I would try to make sure I was visiting Lyall during the times the Doctors would do their rounds, and I would respectfully give my bedside observations to his medical team and try to keep updated on his progress and next steps. They in turn would help guide me on behavioural things to watch-out for and what to take seriously and what to ignore. His medical team made me feel like an important part of their team and often acted, ordered tests, if I had raised a concern about a new symptom. They listened to my concerns and briefly looked at my daily notes (I'd have to keep these brief otherwise they wouldn't read them through).

After all serious diseases, viruses, disorders, and neurological conditions were ruled out, he was diagnosed with Delirium. It then became a challenge to determine what was causing it so they could pull him out of it. Every day they changed something to see if it would help and I'd provide bedside feedback on whether it had made a difference or not. Then the next day they would try again, and again, and again.

One evening when I was looking back through all my notes, it occurred to me that his condition started to deteriorate about the same time they had changed one of his anti-rejection medications, which happened several days prior to his Cardiac Tamponade event. I read the symptoms of possible allergic reactions to this medication, and they seemed like what Lyall was experiencing. By this time it was 2am, so I phoned the hospital and reported this to the Doctor on Duty, then met with his normal medical team the following morning to discuss further.

By that time, they had already changed his anti-rejection medication, they had also ordered infusions of immunoglobulin as well as a few other minor medicine changes.

The following morning, I walked into see Lyall, and to my complete surprise he was sitting up in his bed playing cards and simply said *"Hi V".* He had totally come out of his Delirium. To this day his medical team are still not sure what

Lyall and Veronica after his recent stem cell transplant

caused it, there are several theories and differences of opinions, but ultimately, they believe it was a chemical imbalance in the brain that could have been a result of his new medications (or combination thereof) and his compromised immune system. It took three weeks for him to fully recover. Lyall doesn't remember the Delirium, he refers to this period as his visit to *"La La Land"* – one day his fingernails were short, the next day he woke-up and they were long.

Seeing a loved one go through this was totally heart wrenching and incredibly scary. It was made worse being in the middle of COVID-19 and having all the borders closed which stopped other family members from travelling to help support us. But the medical professionals never gave up and kept giving me hope that they would work it out. And they did.

After weeks of rehab for severe muscle atrophy Lyall was discharged from hospital. He was required to stay locally in Sydney as an outpatient until he had completely stabilised on the anti-rejection medication and been given the green-light to travel home to Adelaide. That green-light came at the end of October 2020, a few weeks after the border between NSW and SA had reopened. Perfect timing to avoid the complications of quarantine.

Upon returning to Adelaide Lyall was able to settle back into his own house and routine with his family and continue focusing on rehab. We had a lovely Christmas together with all our extended family. Then in January 2021 the preparations ramped up for his next procedure, the Autologous Stem Cell Transplant.

As I write this article (its mid-February 2021) Lyall is still in hospital and is almost two weeks into the Stem Cell Transplant procedure.

As I did before, I elected to travel with Lyall to Sydney as his advocate. This whole procedure has again been tough on Lyall as a patient, simply because it makes people feel so sick and weak. But we knew it would be hard for him going into the procedure.

Despite Lyall feeling so sick, everything has gone to plan so far without any major complications. I visit Lyall morning and night and try to keep track as best I can on the parameters that are important and keep his family updated in Adelaide. If I need help understanding something, I ask his nurse or medical team questions. But I make sure to be polite, not too demanding, non-judgemental, and sensitive to their time as often they have a lot on their plate, and I don't want to become a nuisance.

My intent is to advocate, support and help – not to make life difficult or unpleasant for anyone. We are all there for the same reason, to help Lyall. If I see something that concerns me, I alert a member of his medical team. If I know a non-routine procedure or medication is scheduled, I follow-up to make sure the wheels are turning and it's on track to occur. If I suspect something has been overlooked or missed, I alert someone – just in case. We are all only human after all and we need to have each other's back, help each other for the good of our common goal.

Lyall's on the recovery side of the curve now, with his immune system ramping up production of new white blood cells from his stem cells that were harvested back in January 2016.

Here I am now, looking back at it all. Lyall's journey has entailed a large range of different treatment options, with varying degrees of success, including participating in multiple clinical trials. These leading-edge medical developments offered hope at times when there were no other treatment options available and fortunately for us several of them delivered.

From Lyall's endeavours over the last five years, support from his advocates, and from an incredible and progressive team of medical experts, he has made it through and potentially forged new pathways for successful treatment of others who have the same diagnosis.

An extended life, long term maintenance of his condition and even a cure is now a real possibility.

To have Lyall still with us today in our view is a medical miracle. I cannot explain the emotions felt by our family and how grateful we are – there just aren't any words.

If it wasn't for Veronica I wouldn't be alive today. She has been remarkable in her generosity, for coming back from the United States, for quarantining, for flying interstate multiple times with me, for the time and effort she has invested in my care. My wife, children and I will be forever grateful to her. ***Lyall Pearce***

Innovators never sleep

The Alfred is renowned for its innovation and one of its key med-tech partners, Abbott, is currently pushing the envelope a little further with research and development of a fully implantable left ventricular assist system as a next generation of its HeartMate circulatory support system.

Abbott recently announced that the company had received 'Breakthrough Device' designation from the U.S. Food and Drug Administration (FDA) for its in-development *Fully Implantable Left Ventricular Assist System* (FILVAS).

The FDA launched the 'Breakthrough Devices Program' in 2018 to help expedite the development and review of submissions for technology that offers significant advantages over existing approved products.

Approximately 6.2 million people in the U.S. are living with heart failure. Because this is a progressive disease, more than 600,000 people each year reach an advanced stage where traditional therapies, such as medication and cardiac resynchronization therapies, no longer work.

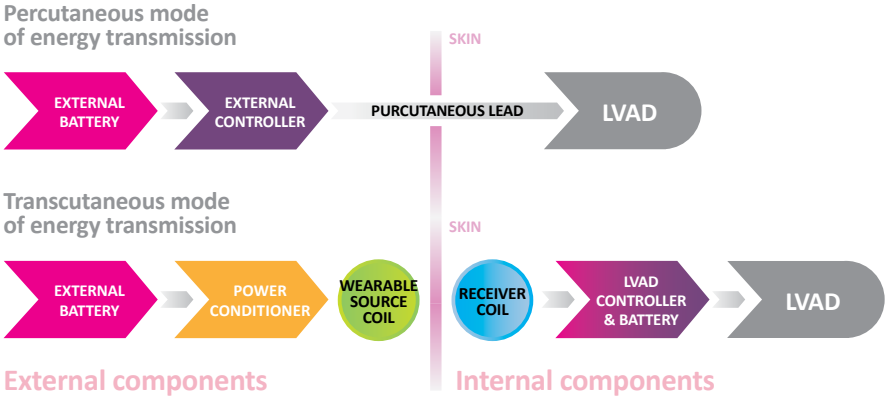
"As the leader in heart failure management, a fully implantable heart pump has been our vision for the tens of thousands of people who progress into advanced heart failure each year," said Michael Pederson, senior vice president for Abbott's electrophysiology and heart failure division.

"The potential for a fully implantable system would mean more freedom and a greater quality of life because there are no external components to be carried everywhere. These advances underscore Abbott's long-standing commitment to develop innovative devices that allow those with heart failure to live their best lives."

Heart pumps are small, implantable mechanical devices that pump blood throughout the body in people living with advanced heart failure. Those living with a heart pump are either waiting for a heart transplant or are not candidates for a heart transplant, and need the life-saving device to pump blood from their heart to the rest of their body.

Currently, left ventricular assist devices are implanted into the body and then powered using an external battery pack or charging port.

Current percutaneous charging LVAD system v future Fully Implantable LVAD system



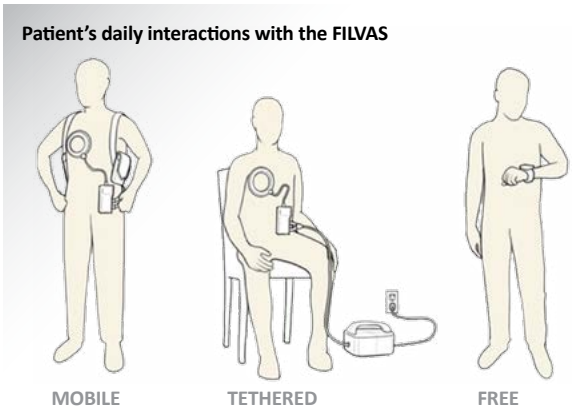


Table and illustration courtesy: www.thoracickey.com/innovation-update

Abbott's FILVAS is in research and development and is not available for sale anywhere in the world.

Abbott's heart failure innovations

Abbott is recognised as a global healthcare leader that helps people live more fully at all stages of life. Their portfolio of life-changing technologies spans the spectrum of healthcare, with leading businesses and products in diagnostics, medical devices, nutritionals and branded generic medicines.

Abbott is pioneering heart failure disease management with innovative solutions like the CardioMEMS HF System, ground-breaking quadripolar pacing technology, MultiPoint™ (MPP) pacing technology and the HeartMate 3 LVAD.

Abbott's HeartMate 3 heart pump, used at The Alfred, is for advanced heart failure patients who are awaiting transplantation. *(Note: Australia does not currently use LVAD technology as a destination device for patients that are not candidates for heart transplantation).*

It is the first commercially approved LVAD with Full MagLev™ technology, which allows the device's rotor to be 'suspended' by magnetic forces. This design aims to reduce trauma to blood passing through the pump and improve outcomes for patients.

BACKGROUND:

Percutaneous – In surgery, a percutaneous procedure is any medical procedure or method where access to inner organs or other tissue is done via needle-puncture of the skin, rather than by using an "open" approach where inner organs or tissue are exposed. *Wikipedia*

CardioMEMS HF System – consists of an implantable, battery-free sensor that is implanted into the distal pulmonary artery to continuously measure the heart rate along with systolic, diastolic, and mean pressures.

Multipoint™ Pacing (MPP) – via a single left ventricular lead improves acute left ventricular (LV) function and response to cardiac resynchronization therapy (CRT).

SOURCE: Abbott, 4 February 2020

For further information:
www.abbott.com

In the next edition of the *Circulator,* read about a new and less invasive surgical approach for Abbott's HeartMate 3 LVAD pump to help patients avoid open heart surgery

HLTTV is pleased to have financial support from Abbott for this edition of the *Circulator,* allowing an extended print circulation to Cardiac Clinics and GPs in Victoria, South Australia and Tasmania to promote knowledge and information about heart transplantation.

Stories of strengt showcased in ne

A new podcast – Let's Talk Organ and Tissue Donation – shines a light on the personal experiences of organ and tissue recipients, donor families, living donors and expert medical and nursing specialists, helping to raise awareness about organ and tissue donation.

"Hi, I'm James Sheppard and I'm here for a heart transplant."

These were the words of heart recipient James Sheppard when he arrived at The Alfred Hospital's Emergency Department after receiving the call he'd been waiting for – a donor heart had become available.

James is one of many people who share their personal story of strength and resilience in a new podcast by DonateLife Victoria, who facilitate organ and tissue donation across the state.

The podcast – ***Let's Talk Organ and Tissue Donation*** – shines a light on the personal experiences of organ and tissue recipients, donor families, living donors, and expert medical and nursing specialists, helping to raise awareness about organ and tissue donation.

The podcast offers a unique insight into topics such as rare transplant cases, the donation journey, and the life-changing moments for everyone involved.

For podcast host and Bendigo radio presenter Michael Billings, the podcast runs very close to his heart, after he lost his father while on the wait list for a liver transplant.

"After losing my father before he had an opportunity to receive a liver transplant, I have learnt there are so many facets to organ donation," said Mr Billings. *"The one thing that never ceases to amaze me is the selflessness of families who choose to think of others amidst their own grief. It's the greatest act of generosity."*

A personal story

In the first episode, Michael talks candidly to heart recipient James, whose life completely turned around almost three years ago after receiving a heart transplant.

During his early twenties, James lived a normal life, working full-time and socialising with friends. By his mid-twenties, James started experiencing the pounding of an irregular heartbeat that would leave him feeling weak and exhausted.

"It was like having a drummer inside my chest who didn't know how to keep a beat," James says.

James was initially diagnosed with atrial fibrillation, a type of arrhythmia in which the heart beats irregularly and fast, reducing the heart's ability to pump blood properly and increasing the chance of a blood clot forming in the heart.

"I was essentially running a marathon lying in bed all day," says James. *"It was absolutely exhausting."*

James underwent a number of treatments and surgeries, including a catheter ablation and later, open heart (bypass) surgery, both of which were unsuccessful. *"It was a pretty grim time,"* he says.

James was eventually diagnosed with restrictive cardiomyopathy – which became heart failure – a heart condition that sadly both his grandfather and uncle passed away from.

"Finally, we had something – we had a diagnosis and it was something we could start putting our energy and time into, to work out what we needed to do to correct it. The short answer was, I needed a heart transplant."

James describes the following months as a *"crazy time"* filled with appointments and physical preparation.

"My full-time job became staying well enough so that when the phone call did come, I'd be ready to go," he says.

"It's the kind of experience where you know where your phone is all the time. You know how much charge you have left in your phone, you know where the charger is, you know if you're heading

th amid adversity w podcast

out of range. You don't turn it off and you don't put it on silent. I needed to make sure I was going to get that call," says James.

When that precious moment came for James – which he describes as surreal – in the shock and excitement of it all, he drove himself to hospital, which he laughs about now.

From transplant, to Transplant Games

James describes waking up after surgery as *"amazing"* because he knew he was alive; however, he recalls the peculiarity of not *"feeling"* his heart.

"I felt nothing," he says. *"For so long I'd had this irregular heartbeat and a heart that didn't work properly and I could physically feel that. I'd forgotten that it's normal to not know your heart is in there. It's normal to not even know that it's working."*

"For so long I'd had that physical feeling that it was beating out of rhythm and struggling. To wake up and it's silent, there's nothing happening in my chest. I know it's there and that it's working, but I can't feel it. That was incredible," says James.

Only eleven days after his heart transplant, James was on an exercise bike. He was committed to maintain his health and fitness and would soon excel in his rehabilitation program.

Within five months he was participating in the iconic *Around the Bay* cycling event, riding 20 kilometres. Incredibly, he would then compete in the World Transplant Games less than a year later.

James is a great advocate for organ donation and is quick to credit his donor and the donor's family for turning his life around.

"Thank you is not enough," he says. *"I want them to know how happy and how well I'm doing, and hope that they are proud of the decision that they made,"* he says.

"I'd like them to see what an incredible outcome it has been, what an incredible gift it was, and how grateful I am, now and forevermore. I'm living a life that I could have only dreamed of. I'm happy, healthy and that's all because of their gift."

Organ donation is a rare event. Only around two per cent of people who die in Australian hospitals – approximately 1,300 people — meet the criteria required to be an organ donor.

Last year, 1,270 Australians lives were saved through an organ transplant due to the generosity of 463 deceased organ donors and their families.

There are more people alive in Australia today because of organ donation. Register to become and organ and tissue donor at donatelife.gov.au

***Let's Talk Organ and Tissue Donation* is available at donatelife.gov.au/podcast**

A fit, healthy and very grateful heart transplant recipient James Sheppard

Osteoporosis Australia rebrands

Osteoporosis Australia recently announced its official rebrand as 'Healthy Bones Australia' to reinforce the importance of prevention, in response to the concerning 173,000 broken bones sustained by the Australian population last year.[1]

The organisation also called for Australians to "prioritise their bone health", by learning the risk factors for, and how to best prevent, brittle bones and osteoporosis.

This announcement coincided with the publication of an article by Healthy Bones Australia experts in *MJA Insight,* presenting preliminary findings and recommendations from their recent *Inaugural National Consumer and Community Forum.* The Forum was convened to hear directly from people of different ages living with osteoporosis, and to address health system barriers to improving Australian's bone health.

According to MJA Insight article co-author and Medical Director, Healthy Bones Australia, Professor Peter Ebeling AO, Melbourne, given the growing prevalence of osteoporosis and the increasing number of associated fractures, much more must be done to improve public awareness of the importance of maintaining healthy bones, and the diagnosis, and treatment for those "at risk", and living with the disease.

"Concerningly, the prevalence of osteoporosis in Australia is on the rise, with more than 4.74 million Australians over 50 years of age (approximately two-thirds of those aged 50+) living with poor bone health.[1]

"Early diagnosis of osteoporosis is vital to reducing fracture rates, and their subsequent impacts and costs. These osteoporotic fractures cost the Australian healthcare system more than $3 billion each year,"[2] said Prof Ebeling.

The Forum called for heightened community awareness, education, improved diagnosis and management of osteoporosis, including:

- The critical need for readily accessible osteoporosis treatments;
- Improved capture of patients post-fracture through the hospital system, to both diagnose osteoporosis and commence treatment;
- A substantial increase in Australian's awareness of risk factors for poor bone health and osteoporosis; and
- General Practitioners (GPs) to focus more on bone health to prevent osteoporosis and fractures.

"The renaming of our consumer organisation to 'Healthy Bones Australia' reflects our aim – to protect, build and support better bone health for all Australians," Prof Ebeling said.

According to MJA Insight article co-author and Deputy Chair of the Medical and Scientific Advisory Committee, Healthy Bones Australia, Dr Weiwen Chen, Sydney, educating target populations about the risk factors for osteoporosis is critical to ensuring earlier diagnosis of the disease, reducing fracture rates, and curbing their impact and cost.

HEALTHY BONES AUSTRALIA

About Healthy Bones Australia

Healthy Bones Australia, formerly Osteoporosis Australia, is a national not-for-profit organisation, and the leading consumer body charged with reducing broken bones and improving bone health across Australia through community and health professional awareness along with advocating to government to reduce the impact of the osteoporosis nation-wide.

About osteoporosis

Osteoporosis is a disease that leads to reduced bone strength and increased risk of fracture.[1,3,4]

Osteoporosis occurs when bones lose density and quality, leading to weakness of the skeleton.[5] Once a fracture occurs, action must be taken to protect bone health, and the level of bone density is monitored to gauge improvement.[5,6] Importantly, osteoporosis and osteopenia are not just seen in women only.[7] Men account for up to 30 per cent of all fractures related to osteoporosis and osteopenia, and their associated costs.[7]

Key risk factors include a prior fracture, family history, certain medical conditions or medications, early menopause/low testosterone, smoking and high alcohol intake.[2,8,9]

By 2022, around 6.2 million Australians over 50 years of age will be living with poor bone health (either osteoporosis or osteopenia),[1] equating to 183,105 fractures each year. By 2022, a fracture will occur every 2.9 minutes,[1] resulting in 501 fractures per day, 3,521 fractures per week, and 183,105 fractures per year.[1]

By 2022, the projected total cost of poor bone health among Australians aged over 50 years will be $3.84 billion, comprising ambulance services, hospitalisations, emergency department and outpatient services, rehabilitation, aged care and community services.[1] The total direct and indirect cost of poor bone health and its associated fractures over 10 years (2012-2022) is $33.6 billion.[1]

Transplant and osteoporosis

Organ transplantation offers new life to patients who suffer from incurable disease and the problem of rejection of the transplanted organ has been overcome with the use of potent immunosuppressive drugs.

These drugs, although they allow graft tolerance and graft survival, appear to be one of the main factors associated with complications such as development of osteoporosis.

The drugs that are responsible for this bone loss are glucocorticoids and the calcineurin phosphatase inhibitors, cyclosporine and tacrolimus.

The most commonly used anti-rejection medicines that are thought to adversely affect bone are prednisone, tacrolimus and cyclosporine. Based on experimental models, mycophenolate mofetil, azathioprine and sirolimus are not thought to cause bone loss.

The important take-away from this is that regular checks with an endochrinologist and listening to the advice of your transplant team are crucial to you mitigating the effects of life-saving but powerful immunosuppressive drugs.

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8. Unnanuntana, A., et al., *The assessment of fracture risk.* The Journal of bone and joint surgery. American volume, 2010. 92(3): p. 743-753.
9. Pouresmaeili, F., et al., *A comprehensive overview on osteoporosis and its risk factors.* Therapeutics and clinical risk management, 2018. 14: p. 2029-2049.

To learn more about Healthy Bones Australia, head to www.healthybonesaustralia.org.au

TRANSPLANT 2021 ANNIVERSARIES

HEART

FEBRUARY
Ian Gordon 1999
Margaret Neilson 2009
Katrina Rehlaender 1993
John Winter 1992

MARCH
Gary Down 2012
Sue Konieczny 2008
Edward O'Bryan 1990
Matthew Orchard 2014
John Timothy Armstrong 2014
Rod Pulford 2018

APRIL
Nicole Armstrong 2014
Ivan Clark 2015
Graeme Klemm 2019

HEART + LUNGS

APRIL
Carla Bondini 2014 (HL)
Jose Lopez 1990 (HLL)

LUNGS

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

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

APRIL
Christine Flack 2014
Sam Ira 2013
Robert Regan 2017
Bruce Vernon 2015
Benjamin Watt 2017

The Alfred transplants and VADs 2021

Note: these figures are for the period January 1 – April 28, 2021

8

24

1

Both LVAD and BiVAD included in this figure

4

Committee meetings 2021

(Email secretary@hlttv.org.au for agenda items.
Meeting 2/4 - Tues 11 May, 2021
Meeting 3/4 - Tues 10 Aug, 2021
Meeting 4/4 - Tues 9 Nov, 2021
** AGM followed by normal committee meeting*

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

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

Member Events 2021

- **Service of Remembrance**
  Last Saturday in May (Victoria
- **DonateLife Thank You Day**
  21 Nov
- **Xmas BBQ** – Sun 28 Nov
- **DonateLife Week**
  26 July - 1 Aug
  Please note all venues and dates will be confirmed later

Circulator content deadlines

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

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

Are you playing hide and seek with salt?

"Seventy-five percent of the salt we eat comes from processed and packaged foods. You may not realise how much salt is in the foods you eat because many of them don't taste salty."

We're all playing hide and seek with salt. Every day most Australians eat nearly twice the recommended daily intake of salt.

Eating salt increases the level of sodium in your diet. Over time, a high level of sodium in your blood can increase your risk of developing high blood pressure. The danger is when your blood pressure is too high for too long you could be at major risk for developing heart disease.

To beat salt at hide and seek, go to:
www.heartfoundation.org.au/blog/salt-is-putting-your-heart-at-risk

VALE

Barry Katzenberg

21 February 1956 – 21 December 2020

Born and raised in Bulawayo, Zimbabwe, and after attending University in South Africa, Barry was part of a highly successful import/export business in Bulawayo which embedded in him the desire to become a money phycologist (financial planner).

Barry, his wife Heather, and their two children, immigrated to Australia in 1990 and welcomed their third child in 1996. Against all odds, he slowly but surely built Light Financial Services, running his business for 30 years.

Barry joined and ran the Adelaide Chevra Kadisha (Jewish Burial Society) for 30 years, having to step down due to ill health in June of 2020.

For the last 16 years Barry had fought heart disease in many forms, culminating in the chance for a new start with a transplant on the 12th December 2021. Complications following the surgery led to his untimely passing, but the family are grateful to have been there with him, during this time.

There were many happy memories during his life, here in Adelaide, and his greatest joy was celebrating the many simchas (milestones) our family had. He was our Bear, always meeting us at each turn with love, wisdom, and support.

We sincerely thank all those who cared for Dad so lovingly during his final journey, and our family and friends for joining us in saying farewell. It is not goodbye, but 'till we see you again.

Bravo, Barry Bear.

Heather Katzenberg,
Kendyl Katzenberg-Roesler,
Jarred Katzenberg and
Eryn Katzenberg

Peter McDonald

24 May 1949 – 4 January 2021

I'd love to have a drink with Mackie
Cause Mackie was great
He told me lots of stories
My dad and my best make

He taught me how to water ski
How to drive and change a flat
He instilled the love of travel
Adventures off the beaten track

A wicked sense of humour
Always with the best jokes
Could talk with a mouth full of marbles
Around the fire with all the blokes

The one I turned to for any advice
Always told me "She'll be right"
The strongest man I've ever known
He put up one hell of a fight

Thanks for being the greatest Dad ever
My childhood was truly the best
I will never ever forget your face
I hope now you can get some rest

I'll see ya when I'm lookin at ya
Is what you always used to say
I'll cherish every memory I have
And I'll be lookin at ya again one day

Love you always Dad
I'll look after mum for you
Our adventures will go on
Make sure you check up on us too.

by Dani

Just a quick word about a legend of a man
Gathering memories with us
Members of his clan

Life was full of excitement, adventures and fun
Living, working, travelling with me, my sister
Oh and of course my Mum

Taking life serious when at times it was called for
Having gret times, joking and laughing
Always wanting for more

True gentleman, husband, father, friend Mackie & mate
Always caring loving instilling values
And lessons for us to create

A young family of our own to reflect the one we had
Created by what we were taught
From our beautiful Mum and caring Dad

Highs and lows were had, peaks and troughs of life
"Just Cruisin" life's journey with extreme love of his wife

Occasionally stubborn in life, in discussions
Knew when to hold them
Occasionally patient with compassion and care
Knew when to fold them

Was one of the greats
The best you would have had
Sincere love for you Mackie
Your son, who's proud to call you Dad.

by Shannon

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 development 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**

Did you know...

All major religions support organ and tissue donation

donate life

Join the patient portal

The Alfred Health Patient Portal enables our patients to easily access their Alfred Health medical information online.

Through this portal you can easily access your Alfred Health information online, which comes directly from your Alfred Health electronic medical record and is updated by your Alfred Health clinicians.

Using your computer or mobile device, you can access the portal to view your appointments, access test results and message healthcare teams.

Alfred Health's *Patient Portal* provides you with safe, convenient and easy access to your health information online.

You can use the portal to:

- **view upcoming appointments**
- **view pathology results from most tests conducted at the Alfred Health pathology laboratory**
- **view letters sent to you**
- **view your inpatient discharge summaries from any unit**
- **receive secure messages from your healthcare team**
- **your calendar; and**
- **print information from the portal to take to appointments with different care providers.**

Your *Alfred Health Patient Portal* only includes select information related to your care at Alfred Health. If you receive care at other hospitals or healthcare services, this information will not be available in your *Alfred Health Patient Portal.*

Creating your Alfred Health Patient Portal account

To register for a Patient Portal account, speak to your healthcare team. You will receive an invitation to join the portal by email. To access the portal for the first time use the link in this email invitation.

Please speak to your healthcare team if you have questions about the portal or contact the *Alfred Health Patient Portal* team on 9076 5000.

You can opt out of your *Patient Portal* account at any time by simply emailing the Patient Portal team at patientportal@alfred.org.au to cancel your account.

There will be no change in the treatment and care you receive at Alfred Health if you choose not to register for the portal. Your healthcare team will communicate with you about your care and share your health information with you just as they do now.

How to use the Patient Portal

The *Patient Portal* has been designed for people with computer skills of all levels. However, you do need an email address to sign up for the portal.

Once your account is established, you can access the portal through the Alfred Health website www.alfredhealth.org.au or directly at the website below.

Your information in the Patient Portal

Your *Patient Portal* account will include information to help you manage your healthcare and make decisions.

It will include:

- all historical test results
- any new test results, which will be available within 14 days. This 14-day timeframe allows Alfred clinicians to review a test result and contact you in person before the result is released to the portal if required.

Your clinician will discuss your results with you either over the phone or at your next hospital visit, and advise what action you should take based on those results.

Anatomical pathology, genetic testing and tests conducted at other facilities are not available, and results will be provided by your care team.

Please contact your healthcare team if you have any questions or concerns.

Safe and secure information

Alfred Health make every effort to keep your information safe so only the right people can access your information, including the clinicians who are providing your care.

The *Patient Portal* use the very latest in secure technology and information stored within Alfred Health's electronic medical record meets the highest security standards, including encryption and password protection.

You can help safeguard your health information by keeping your password private.

Proxy users – you can choose to give another person, such as your carer or next of kin, access to your *Alfred Health Patient Portal.* This is called proxy access and proxy users have their own logon details that you can remove at any time.

Preparing to register

To register for Alfred Health's *Patient Portal*, you will need the following information – photo ID (such as drivers licence, student ID, passport); full name, date of birth and home address.

For further information

Please speak with a member of your healthcare team if you have questions or contact Alfred Health's *Patient Portal* team at patientportal@alfred.org.au or phone (03) 9076 5000 or visit

www.alfredhealth.org.au/patients-families-friends/patient-portal

ACTIVEWEAR THAT GIVES BACK

BUY TX ACTIVE APPAREL AND KICKSTART AN ACTIVE LIFE FOR A TRANSPLANT RECIPIENT TODAY!

TX ACTIVE

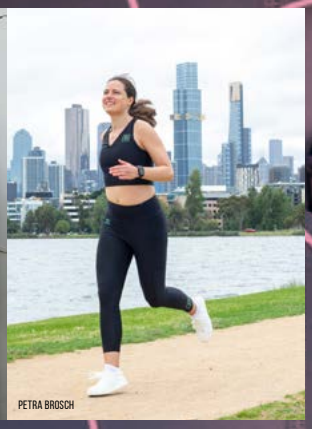

JADE MITCHELL

GIVE THE GIFT OF AN ACTIVE LIFE!

THERE ARE UP TO 300 HEART AND LUNG TRANSPLANTS IN AUSTRALIA EACH YEAR.

OUR CAMPAIGN TARGET IS TO SELL 200 'TX ACTIVE' GIFT PACKS IN ORDER TO DONATE 100 'TX ACTIVE' APPAREL GIFTS TO TRANSPLANT RECIPIENTS AND HELP THEM GET STARTED ON THEIR REHAB JOURNEY AND PREPARE THEM FOR AN ACTIVE NEW LIFE.


PETRA BROSCH AND JADE MITCHELL


PETRA BROSCH

THERE'S TRUTH TO THE SAYING

'LOOK GOOD, FEEL GOOD'

THE GIFT OF TX ACTIVE APPAREL WILL HELP TRANSPLANT RECIPIENTS BY MAKING THEM LOOK AND FEEL TERRIFIC ON THEIR ROAD TO RECOVERY.

TO FIND OUT MORE AND JOIN OUR CAMPAIGN...

WWW.TXACTIVE.COM.AU

KICKSTART AN ACTIVE NEW LIFE FOR A TRANSPLANT RECIPIENT

TX ACTIVE

DESIGNED FOR COMFORT AND PERFORMANCE, OUR RANGE IS SUITABLE FOR BOTH EXERCISE AND LEISUREWEAR. TX ACTIVE IS LAUNCHING WITH A FEMALE RANGE AND PLANNING TO QUICKLY FOLLOW UP WITH A MALE RANGE. WE HAVE PRODUCED THE STYLE OF ACTIVEWEAR YOU HAVE BECOME ACCUSTOMED TO WITH A CREDIBLE MANUFACTURER. WHERE POSSIBLE WE USE SUSTAINABLE MATERIALS.

THE HEART & LUNG TRANSPLANT TRUST OF VICTORIA IS PROUD TO SUPPORT JADE MITCHELL – HERSELF AN ACTIVE MEMBER OF THE TRANSPLANT COMMUNITY IN HER GOAL TO ASSIST OTHERS RECOVERING FROM TRANSPLANT THROUGH HER RANGE OF TX ACTIVE PRODUCTS

LEGGINGS

- DESIGNED FOR STYLE, COMFORT AND PERFORMANCE
- COMPRESSION FIT, NON SEE-THROUGH FABRIC, HIGH WASTED STYLING
- SIDE POCKETS ON EACH LEG
- MADE FROM HIGH-QUALITY RECYCLED POLYESTER FABRIC
- AVAILABLE IN GREEN AND BLACK
- TX ACTIVE LOGO FEATURED ON THE FRONT HIP AND LEFT ANKLE

SWEATERS

SLIMLINE FIT

- FEATURES CREW NECK AND SIDE SPLITS AT THE HIP FOR EASE OF MOVEMENT.
- THE ASYMMETRICAL SHAPE PROVIDES GREATER COVERAGE AT THE BACK.
- AVAILABLE IN BLACK WITH A PROUD MINT-COLOURED CENTRAL TX ACTIVE LOGO.

RELAXED FIT

- FEATURES LOOSER SLEEVES, DETAILED V-FOLD CUFFS, RIBBED NECK AND A WIDE RIBBED WAISTBAND.
- FLATTERING TO ALL BODY SHAPES.
- THE PINK SWEATER COMES WITH A SUBTLE TX ACTIVE LOGO ON THE HIP WHILE THE KHAKI GREEN IS ENHANCED WITH A PROUD CENTRAL TX ACTIVE LOGO ON THE CHEST

RACERBACK TOP – CROPPED & LONG

- CROPPED ALLOWS FOR EASE OF MOVEMENT
- FEATURING SMALL TX BRANDING ON THE LEFT BREAST AND CENTRE BACK
- MADE FROM RECYCLED POLYESTER FABRIC
- THE LONG LENGTH TOP IS TIGHT-FITTING OVER THE SHOULDERS WHICH PROVIDES
- EXTRA COVERAGE AROUND THE TORSO WHEN WEARING
- INBUILT SUPPORT SHELF AND CENTRAL TX LOGO ON THE RACERBACK

T-SHIRTS

- 100% COTTON TEES, SLIM FIT AND STYLISH
- UNI-SEX T'S

"THE GYM CAN BE AN INTIMIDATING PLACE AT THE BEST OF TIMES, LET ALONE AFTER A PROLONGED PERIOD OF BAD HEALTH AND ORGAN TRANSPLANT. I NOTICED THAT SOME PEOPLE AREN'T PREPARED FOR EXERCISE. I WANTED TO GIVE PEOPLE THE CONFIDENCE TO ASSIMILATE INTO ACTIVE LIFE. TX ACTIVE PREPARES PEOPLE FOR REHABILITATION AND MAKES IT LESS INTIMIDATING. OUR GOAL IS TO HELP THEM LOOK AND FEEL GOOD."

JADE MITCHELL
DOUBLE LUNG RECIPIENT AND FOUNDER OF TX ACTIVE

TX ACTIVE

PHONE 0412 438 541 | JADO@THEJADO.COM

WWW.TXACTIVE.COM.AU

JOIN OUR CAMPAIGN AND KICKSTART AN ACTIVE NEW LIFE FOR A TRANSPLANT RECIPIENT

It can be stressful waiting for transplant

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

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

Whether you are a patient or a patient's loved one, waiting for an organ transplant can be an extremely stressful and unpredictable period of time.

For some, though, waiting for a transplant has led to increased feelings of mental strength with minimal to mild psychological reactions, for the majority of transplant candidates and their loved ones, it will be usual to experience a number of worries and stress related to this period of time.

Concerns which have been commonly reported by individuals include; the uncertainty of becoming eligible to be listed, reactions to being listed, uncertainty related to when a transplant will occur, anxiety about life and death, mental burnout due to fatigue, being "chained" to a mobile phone 24/7, difficulties engaging in meaningful activities, family stress, financial hardship, physical discomfort, and overall the person's perception of the transplant procedure as well as post-operative outcomes *(Vermeulen et al., 2005; Bjork & Naden, 2008; Ivarsson et al., 2012).*

Additionally, transplant worries have also been reported to relate to the donor and their family as well as the rehabilitation required post-surgery. These concerns tend to be precipitated by the fast paced work up medical process involving many physical assessments and appointments which occur locally for some but for others, interstate and away from home.

It is important to note that psychological status pre-transplant has been linked to post-transplant outcomes and hence why it is critical to look after yourself during this period of time.

To do this, I would recommend the following 10 strategies to help you and those around you to cope during the waiting period. Please note, however that there are many methods to do this and effectiveness will vary from person to person, depending on many factors.

My aim is to share with you, what patients and their loved ones have said they have tried and found to be helpful and hopefully they will be for you too.

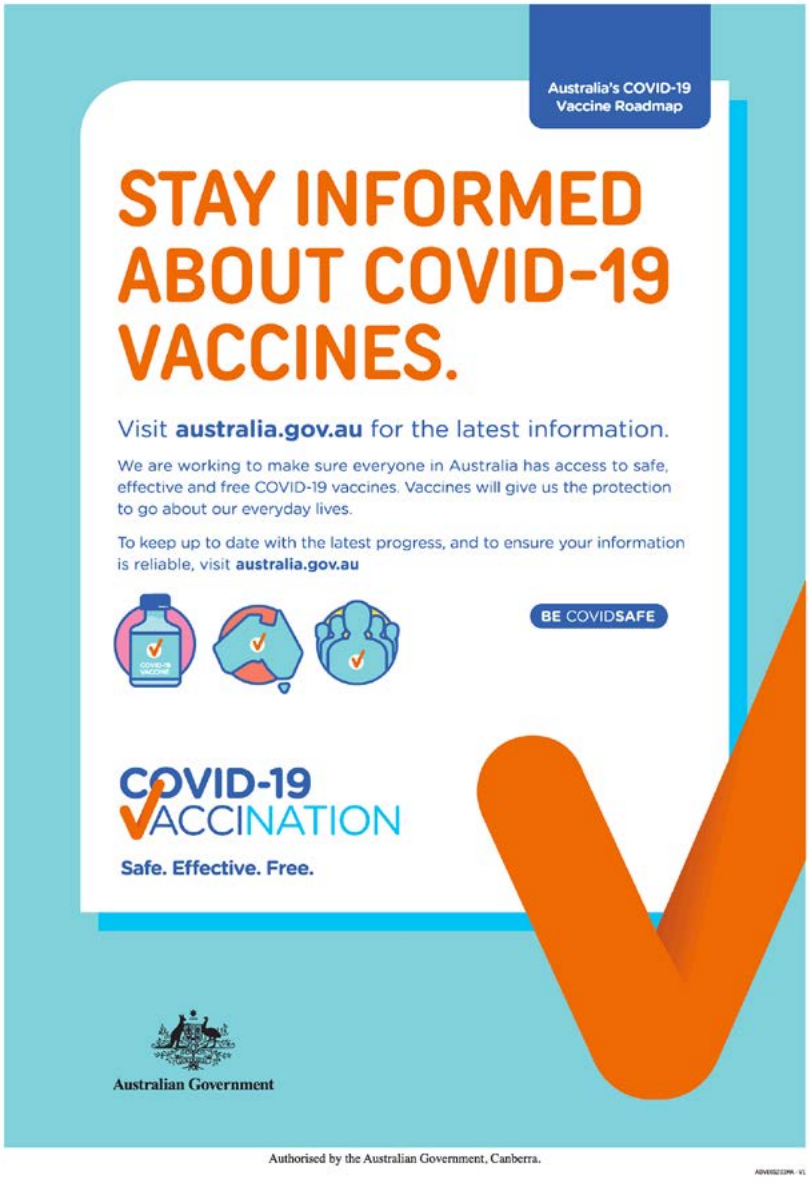
1. Connect with loved ones and take some time to discuss your feelings about a potential transplant and ask them to share their thoughts. Giving some 'air time' each day to this discussion can assist with coping with any worries related to this time and to troubleshoot any potential issues that can be prevented. It would, however, be important to limit the time spent each day talking about this so that once a discussion is had that the conversations can also then allow for opportunity to discuss other important life topics.
2. Speak to others who have waited for a transplant- what helped them through that time? It is important to note to balance your experiences and perceptions with their feedback.
3. Remain present and take it one day at the time- ask yourself, what is one thing that I can do today for me? Make a commitment to yourself and follow through!
4. Keep a diary/journal/video log of your journey and thoughts, allow some time to record what worries you may have and discuss these with people you trust.
5. Fast forward to beyond the transplant – ask yourself how would you like to remember what life was like while you were waiting? Use this to set some small goals, such as completing a brief course, making a video for your loved ones, trying a new hobby, engaging in some relaxation training etc.
6. *"Turn the Mind"* if you are feeling worried about your health, shift your mind to other things, such as listening to music, watching a movie, listening to an audiobook, practicing some photography or a new craft. Use this as a time to build up a repertoire of tools that you can take with you to help in the future – such as printing some picture that you have taken so you can reflect on these while in hospital in the future to promote positive feelings.
7. Use a list of thought statements to evoke positive feelings and behaviours. Examples may include *"I am stronger than my fear", "this too is temporary", "this too will pass".* Best statements will be those that you can personalise for you.
8. Remember each person will have a different experience – whether it's a new job, having a baby, learning to drive, overcoming a health issue – all of this will be different for each person.

   Hence waiting for transplant and a future transplant will also be a unique experience for each person.
9. Think about the importance of small steps.
10. Set a daily routine to help manage your movement, exercise and self-care. Stick to this routine as much as possible.

Remember speaking to someone whether it is a friend, family member, counsellor or psychologist is a great way to unload stress during periods of uncertainty. There are also helplines available to speak to someone at any time:

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

HLTTV thank Susanna Venn from Northcote for her generous GoFundraise donation. Susanna raised $440 in honour of Louisa Walsh, who recently celebrated her 40th birthday – Louise is a previous HLTTV President and Susanna's cousin. ***Photo above shows Susanna (left) congratulating Louisa on her birthday.***



Faith

Despite some recent hiccups Melburnians are still emerging from the dark days of lockdown. Some, taking giant leaps, putting anxiety behind them. Others, taking cautious, tentative steps, aware the pandemic hasn't left us, unsure if we should be kissing, hugging, or even touching yet.

Sitting recently with my sister in a café, Melbourne was luminous in all its former glory on this sparkling Sunday afternoon; a sense of indomitability palpable. We were back, embracing what Melburnians do, sipping on our wine and lattes, engaged in animated conversation with friends.

Perusing the scene I flashed back to this same place only a few short months ago. It could just as well have been a world away, a different universe. Another Sunday on a bitterly cold winter's day, pairs and small family groups only, socially distanced, peering out with fear from above their masks as they waited for take-away pizza. Did we then dare to imagine this post-lockdown reality that has allowed us to welcome the much longed for new year?

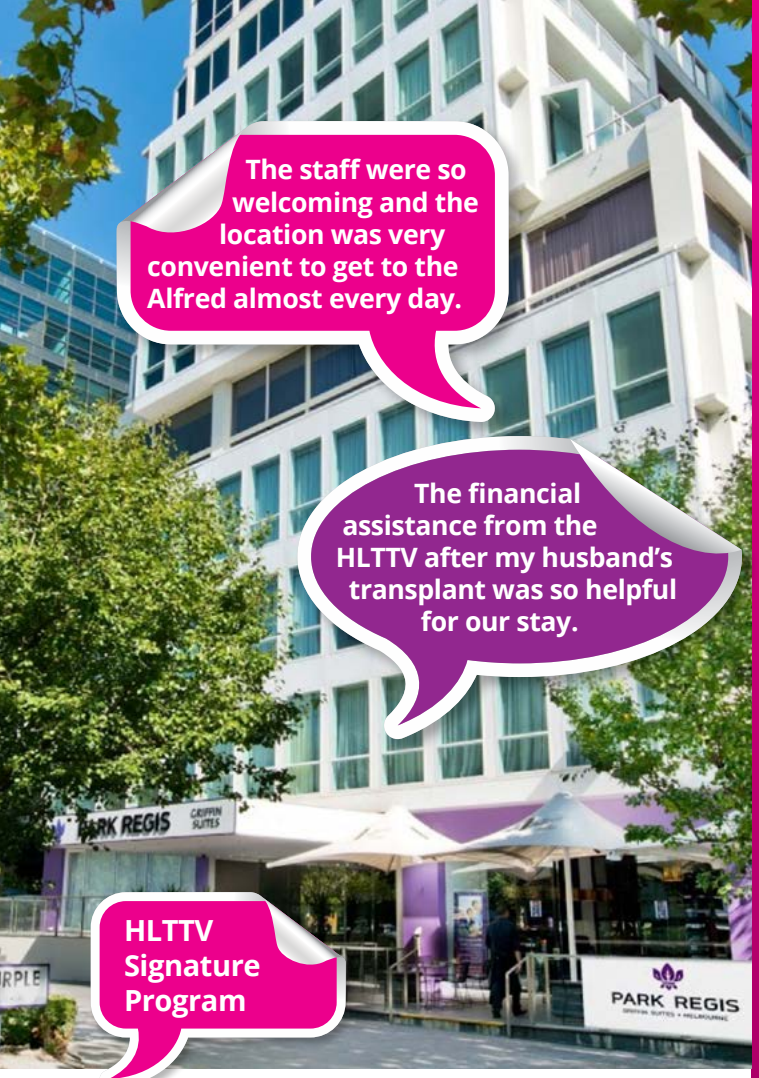
As my eyes scanned the crowd I spotted someone from my past. It'd been a few years, so I wasn't sure it was him. I scribbled a brief note which I had delivered by a waitress. Within minutes he'd approached my table, confirming it was most definitely him, with a kiss on each cheek. This was no ordinary man I'd crossed paths with previously, but a man of exceptional skills and accomplishments, a hero in the true sense of the word. Saving lives is his role in life, an eminent professor, a surgeon heading one of Melbourne's leading transplant units. Warm and humble, just as I'd remembered him, he spent some time chatting with my sister and me. Together with his partner, a transplant coordinator, another vital member of the team behind the incredible story of organ transplantation.

Hero, a word often overused these days, like genius, but one that can perhaps more rightfully be applied through these days of coronavirus. We've seen them on our television screens, camouflaged in their PPE, working tirelessly at the coal face, in hospital wards, in ICU's, delivering food packages, in crisis centres, manning phones at COVID Helplines,

As I took in this novel and yet still familiar sight of relaxed Melburnians doing what they loved on this Sunday afternoon, I wondered how many other such heroes were amongst us, immersed in the crowd, their heroism not visible, yet integral to what had made this day possible.

We have come this far, the sun has shone again and with vigilant steps our journey will continue.

By Janine Joseph,
Melbourne writer



HLTTV Second Chance Accommodation Program

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

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

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

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

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

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

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

PARK REGIS StayWell leisure inn

The HLTTV provides a wide range of support

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

Our services and programs include:

Second Chance Accommodation Program (SCAP)

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

Donations to The Alfred

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

Fitness Grants

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

Emergency Financial Assistance

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

Heart to Heart Respite House (Barmah, Vic)

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

Information and support about transplants and organ donation

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

Peer Support

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

Social events for members of the heart and lung transplant community

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

Visit us at www.hlttv.org.au

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

Your membership counts

Heart and Lung Transplant Trust (Victoria) Inc

PERSONAL DETAILS

Name | Partner's name (if applicable)

Address | Postcode

Postal address | Postcode

Telephone | Mobile

Email | Date of birth

NEW MEMBER

I wish to become a member of the Trust ☐

EXISTING MEMBER

I wish to renew my membership ☐

CIRCULATOR NEWSLETTER

I wish my copy to be emailed ☐

I wish my copy to be posted ☐

MEMBERSHIP TYPE

RECIPIENT

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

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

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

OR ***PRE-TRANSPLANT*** (Waiting list)

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

Signature | Date

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

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

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

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

Please return this form to:

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

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

HLTTV

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

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