

The *Circulator*

Heart & Lung Transplant Trust of Victoria Magazine | Edition 105 | Winter 2024



His parents named him David 'Hope' as they already knew the challenges he was about to face.

"Can I get a soda?"

Those first words from the recipient of an historic world-first Australian designed titanium artificial heart signalled an exciting new era in heart transplants. **Page 37**

New Transplant Registry

Australia & New Zealand Heart Transplant Registry will play a crucial role tracking and evaluating health information for individuals facing health issues. **Page 45**

What the name suggests

A respite house for use by pre and post heart and/or lung transplant patients and their carers. The Heart to Heart Respite House in Barmah is a relaxing, safe haven. **Page 58**

**The Heart & Lung Transplant Trust
Incorporated in Victoria**

A0037327C

ABN 68 585 966 022

Postal correspondence

PO BOX 25036,
Melbourne, Victoria 3004

Online presence

Web hlttv.org.au

Social [Facebook@HLTTV](https://www.facebook.com/HLTTV)

Established 1994

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

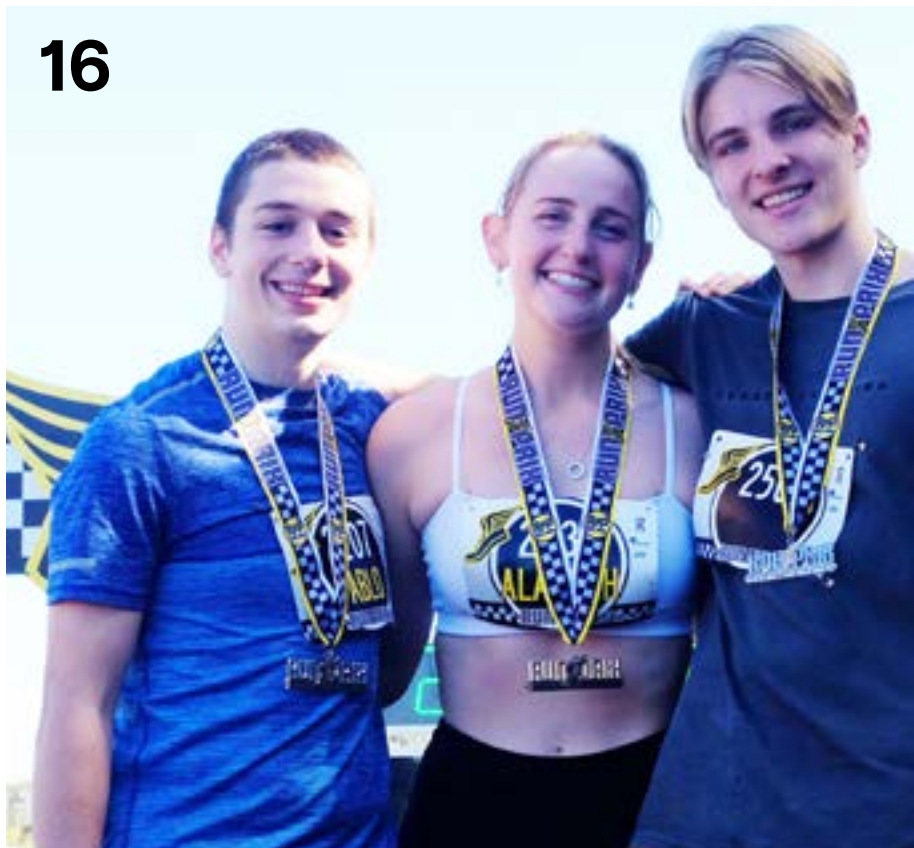
Our Vision is for a bright and active future for all those involved with or in need of a heart or lung transplant. We actively encourage organ donation and support The Alfred Hospital Melbourne, the Transplant Team, patients, recipients, their families and carers throughout their journey.



We support and promote



theAlfred





12

Highlights

Jimmy enjoyed his cruise ship holidays
Page 9

Mending broken hearts: The next generation of implantable devices
Page 12

Running for his life
Page 16

I am one of the lucky ones because of the selfless donation heroes
Page 20

Unbreakable Glass
Page 24

The artificial heart set to transform medicine—and the Aussie who invented it
Page 28

Jose and Richard both celebrate over 30 years post transplant
Page 42

Remembering Carol Darroch
Page 48

A promise made is a promise kept
Page 55

Edition 105 Winter 2024

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

Cover image: The Glass family from Morphettvale in Adelaide, celebrating their son's successful heart transplant in 2019
Printed on 100% recycled paper

President's message

We have much to be thankful for and even more to celebrate during the HLTTV's 30th anniversary



Hello everyone and welcome to the Winter edition of *The Circulator*, brilliantly curated by our editor Graeme Klemm.

My name is Tessa Keegel and I'm the current president of the HLTTV. I was privileged to have a heart transplant in December 2020 and have been a member of HLTTV since 2021.

2024 is the 30th Anniversary of the HLTTV, we have achieved so much in our 30 years. We have already started with our 30th year Anniversary celebrations and have some more events planned where I hope we can all connect as a community.

As well as the 30th Anniversary of the HLTTV, 2024 is the tenth anniversary of the first *Tour De Transplant*, a bicycle tour organised by the HLTTV and led by Australian professional cyclist Phil Anderson. In 2014 the first *Tour De Transplant* raised \$250,000 and was instrumental in funding our *Second Chance Accommodation Program*.

Since 2012 HLTTV has worked to provide funding support for accommodation costs for people post-transplant who live more than 100 km from The Alfred.

We started with support for two apartments, this number increased thanks to the funds raised from the 2014 and the 2016 *Tours* and has been maintained as our flagship transplant recipient support program.

The challenge of fundraising is ongoing for the HLTTV, but we can celebrate the incredible efforts from people such as **Jen Pope** (pictured below) who participated in the Half Marathon on Sunday 21 July and raised almost \$5,000 for the *Second Chance Accommodation Program*.



Jen was running to support her aunt **Tracy King** who received a double lung transplant in January this year. Tracy was able to watch Jen run past Fawkner Park in front of The Alfred.

The Circulator also provides the story of **Alannah Rogalsky** who raised over \$5,000 for the *Second Chance Accommodation Program*.

We have also been supported through successful grant funding from a range of philanthropic trusts, such as **The Caretta Mason Trust**, which has pledged to provide \$5,000 per year in 2024, 2025 and 2026, as well as **The Betty Radford Trust**, which provided \$5,000 in 2024.

These funds have come through at a crunch time for the HLTTV. COVID-19 made it so very difficult for us to raise money, but through the hard work and generosity of all our supporters we have successfully been able to keep funding the *Second Chance Accommodation Program*.

We have also made the decision to slightly increase the annual HLTTV membership fees from \$15.00 per year to \$20.00 per year. A reminder that membership fees are due from July 2024.

The Circulator has an article on the Heart-to-Heart House, a respite house in Barmah which is available to the transplant community as a holiday getaway. We need more people to make use of the Heart-to-Heart house and I would urge anyone who would like to have a holiday in this Murray riverside location to consider making a booking. You will find details at <http://www.hearttoheart.org.au/>

The Circulator also has stories recognising the full lives that our members have been able to live post-transplant. We hear from our members **Jose Lopez** and **Richard Metzke**.

And we also remember members of our community who have died, including **Jimmy Spooner** and **Carol Darroch**, whose lives we celebrate.

The Circulator has an article about organ donation status on drivers' licences. Is it time to return to a national approach to organ donation status being represented on a driver's licence?

We also feature an article about an exciting new initiative, the Australia and New Zealand Heart Transplant Registry (ANZHTR) and how the ANZHTR are partnering with people who have lived experience of heart transplants in developing reporting tools.

I'm sure you will be excited to read stories about the exciting developments and challenges of new artificial heart devices. What do these advances mean for our community? How will we engage with these new technologies?

We have many stories and much to celebrate about our community and the work of all our talented and committed members. Thanks especially to the HLTTV Committee especially to our Vice-president **Martina McArdle** for everything she does, our Secretary **James Ure**, our Treasurer **Sue Laksassi**, our Membership Officer **Wanda Moyle**, **Sam Ira**, **Petra Brosch**, **Claude Turco**, **Trudi Jones**, **Gaylynn Pinniger** and the editor of *The Circulator*, **Graeme Klemm**.

Please consider nominating for the HLTTV committee. We hold four meetings a year with meetings held over the internet so committee members can be located anywhere in Australia. It would be great to have more committee members, especially those who have first-hand experience of using SCAP. Please get in contact with me at president@hlttv.org.au if you are interested in getting involved in the committee or with other HLTTV activities.

I hope to see everyone at the end of year BBQ and fund-raising walk on Sunday the 24th of November. Looking forward to continuing the celebrations for the 30th year of the HLTTV.

2024 HLTTV Committee



Tessa Keegel
President
president@hlttv.org.au



Sue Laksassi
Treasurer
treasurer@hlttv.org.au



Wanda Moyle
Membership
0435 743 146
membershipofficer@hlttv.org.au



Martina McArdle
Fundraising/H2H House
0409 957 492
martina@hlttv.org.au



James Ure
Secretary
0419 395 236
secretary@hlttv.org.au



Petra Brosch
0406 497 603
petra.broschw@gmail.com



Graeme Klemm
The Circulator
0421 327 096
graeme.klemm@outlook.com.au



Sam Ira
0416 198 119
sam@hlttv.org.au



Claude Turco
Patient support
0418 398 587
claude.turco@optusnet.com.au



Gaylynn Pinniger
0427 552 022
gaylynn.pinniger@gmail.com

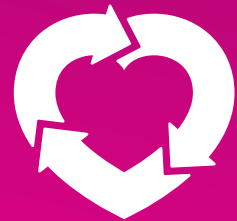


Trudi Jones
trudi.jones76@gmail.com

Heart & Lung Transplant Trust of Victoria Inc Postal correspondence

Heart & Lung Transplant Trust of Victoria Inc
PO BOX 25036, Melbourne, Victoria 3004





DonateLife

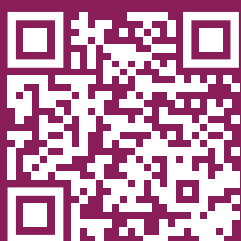
REGISTER AS AN ORGAN AND TISSUE DONOR TODAY

[DONATELIFE.GOV.AU](https://donatelife.gov.au)



**BE THE REASON SOMEONE
ELSE GETS A SECOND
CHANCE AT LIFE**

SCAN TO REGISTER



FATHER PHAM RECEIVED A LUNG TRANSPLANT

Secretary's notes

Inspired by my wife and stalwart of the Heart & Lung Transplant community, I joined the Trust to contribute



Hello, my name is James Ure and I am now the new Secretary for the Heart & Lung Transplant Trust of Victoria (HLTTV). I have been aware of HLTTV and its important place in the transplant community since my beautiful wife, Maarit Moilanen, had a heart transplant at the Alfred Hospital in 2010.

Maarit was an HLTTV committee member for a number of years, and then became HLTTV Secretary in 2018. Sadly, Maarit passed away about 18 months ago, but the heavens above prompted me at the last annual general meeting to volunteer to pick up the secretarial baton, and continue her work. I am really pleased to take over this role, and I look forward to engaging with the transplant community – recipients, their carers, families and friends – in the 30th year of HLTTV's existence.

I know that Covid, and the lockdowns and other restrictions required over several years, had a significant impact

on all communities, including the transplant community and HLTTV. It was difficult to engage with the HLTTV members, to offer social events to allow its members, carers, families and friends to meet, and for HLTTV to raise necessary funds to support important HLTTV initiatives such as (i) the *Second Chance Accommodation Program* (SCAP), and (ii) emergency support and financial assistance to pre- and post-transplant recipients and their carers and families.

As we now emerge from COVID restrictions and their impacts, the HLTTV committee hopes to be able to re-engage strongly with the transplant community, provide opportunities to socialize and celebrate together, and look to encourage HLTTV members to participate in and support HLTTV fund-raising efforts to continue to sustain important initiatives such as SCAP and emergency funding for recipients.

The new Financial Year commences on 1 July 24, and annual membership fees for HLTTV will again fall due at this time.

We will be sending out membership renewal reminders shortly after this.

We will generally communicate with our members via email.

If your email address has changed over the past 12 months, or if you haven't been receiving any emails from HLTTV in the past 2-3 months, can you please let me know so I can update our HLTTV membership database. Please notify me of any changes via the following email address: secretary@hlttv.org.au

Also, if you have:

- 1 any issues you would like to raise for consideration by the HLTTV committee,
- 2 any suggestions for social or other events for HLTTV members and families, or
- 3 any ideas for fund-raising initiatives that the committee should consider,

please also forward these to the HLTTV committee via the Secretary email inbox at: secretary@hlttv.org.au

**All the best,
James Ure**

HLTTV 30 Year Anniversary

2024 represents 30 years since HLTTV was created and the committee continues planning for some events later in the year to celebrate this milestone with all present and past members of HLTTV and the transplant community.

We will communicate with you more in relation to these events over the next few months and look forward to catching up with all past and present members to celebrate this milestone.

If you do not wish to receive emails from HLTTV, please let us know by return email, or to secretary@hlttv.org.au

V A L E



Jimmy enjoyed his Cruise Ship holidays

Jimmy Spooner's heart transplant gave him the chance to enjoy trips away with his wife Monika.

Jimmy was 59 when he had his heart transplant in 2004. Late last year, although not feeling very well, he agreed to share his story. Sadly he didn't get to see it in print. He passed away on 22 December 2023. We will miss Jimmy at our BBQs.

My long journey began when I was working on the Railways. I came home with bad tightness in my chest. It felt like a rope around my body under my arms being pulled tighter all the time.

On the third occasion I got the train home and drove to my then Doctor.

He sent me home telling me it was indigestion and to take some Alka-Seltzer.

That same week, on the Friday night (Melbourne Cup Weekend), I came home from work and went over the road to have a beer with my neighbour. He was putting his car away. I felt very clammy and was sweating profusely. He came out of his garage to find me lying on the road having a heart attack.

He rolled me off the road and started thumping my chest. I started to revive a bit. As he was rolling me off the road

my wife Monika came driving around the corner at about 8.30 pm from work as a Chef.

She had said she would one day find me drunk in the gutter! My neighbour said that the beer she could smell was on him and that I had not had a drink.

Rather than wait for an ambulance they took me to the Dandenong Hospital. Monika drove our LH Torana and my neighbour continued working on me. They both now recommend that calling an ambulance is wiser as the Paramedics have equipment which can help treat the patient on the

way to hospital. Monika rushed into the Emergency Department and said that her husband is having a heart attack. They came running out with a trolley.

Once I was hooked onto the machine they could see I was having a massive heart attack. After two or three weeks in hospital I was sent home. Boydie, my old cat, was very happy to see me. He wouldn't eat for Monika. He ate everything that I gave him. He used to sit under my sun lounge with me.

Eventually it was recommended that I have bypass surgery. The first bypass operation lasted about fourteen years. Then another bypass was needed to keep me alive until a heart became available. This lasted about 18 months. I also had a defibrillator.

We went as usual to our neighbours on the Friday night. Monika gave me a glass of water. Then her phone rang. She grabbed my water. The call was to immediately come to The Alfred. I was so scared.

When we got to Emergency they were all waiting. I was barely alive.

I did have the opportunity earlier for a piggyback heart but decided to wait for the 'Rolls Royce' even though there was a chance I wouldn't make it.

After my transplant I needed dialysis for a while. When I woke up Monika asked me if I knew what day it was. I said Saturday but it wasn't the next day, it was a week later.

Writing a thank you letter to the donor family was the hardest letter I have had to write. You had to consider all their feelings. But eventually it was sent. We received an answer some time later. My donor had a massive aneurism during a sports match. I found out he was from interstate and was 38 years old. He was the father of three teenage children. Tests show my heart is strong.

We visited Monika's family in Germany.

**DONATE
A MINUTE.
DONATE
A LIFETIME.**

**REGISTER AS AN
ORGAN AND TISSUE
DONOR TODAY**



We enjoy Cruise Ships and have wonderful memories. On one trip we joined the Cruise Ship in Hawaii and visited a number of Pacific Islands with the destination being Sydney.

We met Jim Nabors (of Gomer Pyle television fame). We enjoyed his company. We also met Laurie Lawrence, Swimming Coach.

My life has changed in the past couple of years. I had a fall in the garden and Monika took me to Emergency. It was dark when we came home. I was supposed to wait in the car because I had my arm in a sling and Monika wanted to turn the lights on to make it easier for me. But I didn't listen to her.

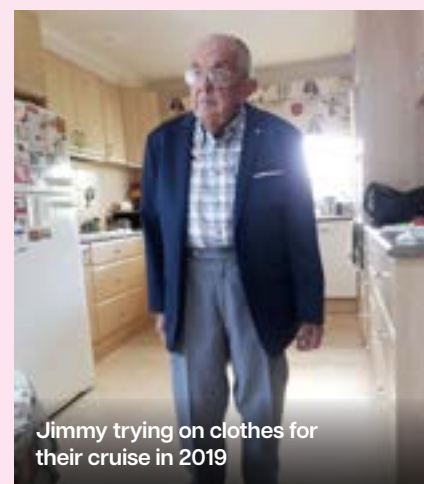
Unfortunately when I was following her up our front steps I fell backwards and hit my head on the concrete.

An ambulance was urgently needed. Monika insisted that the best place for me to be transported to was The Alfred. I was very sick and was treated for a brain injury. A lot of time was

spent in both The Alfred and Caulfield Hospital Acquired Brain Injury Unit under Dr Proudlove.

Recovery through Physio was important. I still go to a Physio in Hampton. At the Physio Room I see Linda Rigby. I would recommend her to everyone.

Without Monika's help and of course all the medical staff, I would never have done so well.



Jimmy trying on clothes for their cruise in 2019

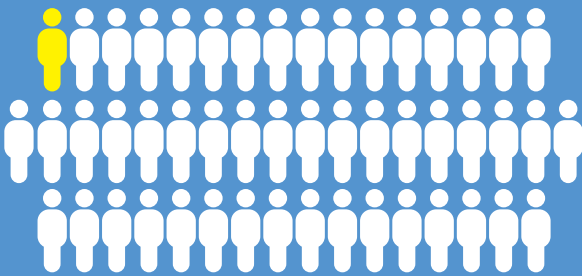
HEART FAILURE



Heart failure affects more than 64 million people worldwide and the prevalence is rising



Heart failure is currently estimated to affect 300,000 Australians with over 30,000 new diagnoses every year



Near 1 in 50 Australians die of heart failure each year



According to official Donate Life statistics, only 129 heart donations were made in Australia in 2023



There are over 60,000 hospitalisations in Australia each year for heart failure

Current fate of patients:

50 to 75%

of heart failure patients die within five years

ARTIFICIAL HEART FRONTIERS PROGRAM

Transforming the future for patients with heart failure



Led by Monash University the Artificial Heart Frontiers Program is a multidisciplinary consortium applying cutting-edge technologies to transform the healthcare of people with heart failure, with a firm commitment to revolutionise implantable heart devices in Australia that will save countless lives now and in the future.

The Artificial Heart Frontiers Program presents a powerful, exciting opportunity from which to deliver urgently needed solutions, focussed on the application of mechanical circulatory support (MCS) devices, for people suffering from untreatable forms of advanced heart failure.

They are a multidisciplinary consortium that applies cutting-edge technologies to transform the healthcare of people with heart failure. They are committed to developing game-changing innovative medical devices that will improve and save lives.

Revolutionising heart failure therapies

The Artificial Heart Frontiers Program is developing a suite of next-generation devices to support all heart failure patients. They have partnered with BiVACOR Pty Ltd to assist in the commercialisation of their Australian-invented total artificial heart (TAH), a complete long-term replacement of the native heart. BiVACOR's technology



MONASH
University



AHFP
ARTIFICIAL HEART
FRONTIERS PROGRAM
Led By Monash University

will also be leveraged to develop a series of next-generation devices for the treatment of segments of heart failure patients that now have few or no treatment options.

The devices will save the lives and improve the quality of life of many of the 300,000 Australians, and millions worldwide, now living with significant physical impairment due to heart failure. In the process, they have a unique opportunity to build a world-leading domestic cardiovascular device industry supported by Australia's excellent science, research, and clinical expertise.

Heart failure in Australia

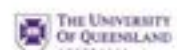
There is an urgent need for innovation in the clinical care of heart failure patients in Australia and around the world. Heart Failure leads to high morbidity and mortality, and it is a substantial burden to healthcare systems.

Program benefits to Australia

The Artificial Heart Frontiers Program will be a game-changer for the treatment of heart failure in Australia. It is expected to reduce the numbers of deaths by heart failure while improving their longevity and quality of life. The program is also expected to drive significant benefits to the Australian economy through savings to the healthcare system, job creation and labour force benefits and additional revenue.

Through seamless integration, the Artificial Heart Frontiers Program will deliver to Australia a vital, energetic ecosystem which will encompass an expert research, developing and manufacturing environment for the production of next generation, medical devices supported by the expansion of a highly-trained, job-ready cohort of skilled workers.

www.ahfp.monash



Mending broken hearts: The next generation of implantable heart devices

*Extraordinary progress is being
made by Australian medical teams*

Medicine and Health | 20 February, 2024

FEATURING:



David Kaye

Adjunct professor, Monash Alfred Baker Centre for Cardiovascular Research, Monash University



Shaun Gregory

Associate Professor and Deputy Head, Department of Mechanical and Aerospace Engineering

In Australia, heart failure affects 500,000 people with more 50,000 new diagnoses annually. Globally, more than 64 million patients are affected, and with an aging population the prevalence is rising.

Heart failure is typically a progressive condition and patients commonly experience worsening quality of life, frequent hospitalisations and, ultimately, reduced life expectancy.

Existing heart failure interventions

In the advanced stages of heart failure, heart transplantation continues to be the best long-term treatment, yet patient need greatly exceeds the availability.

But there is an alternative solution; Mechanical Circulatory Support (MCS) devices. MCS devices are small mechanical pumps that either assist the native heart in pumping blood, or completely replace the native heart with a blood-pumping device.

MCS devices are increasingly used to treat patients with heart failure, however, problems continue to be experienced by MCS users.

These relate to design limitations, including:

- Poor physiological adaptation due to single speed or pulse rate pumps that do not meet the patient's changing blood flow and oxygenation requirements
- Poor blood compatibility due to mechanical design systems that change and damage blood constituents and expose patients to severe postoperative complications and increased risk of mortality
- Infection due to permanent skin-crossing components used to power devices
- Size limitations - MCS devices are not suited to all forms of heart failure, particularly those in older patients, some women and children, and
- Challenges in using MCS devices where both the left and right sides of the heart are severely damaged.

The daily routine of patients with an MCS device is one of increased cognitive and emotional load, with heightened awareness and relentless anticipation, physical burdens, and practical constraints.

Article continues on page 14...





The BiVACOR Total Artificial Heart (TAH) is designed to take over the complete function of a patient's failing heart.

Powerful

The centrifugal pumps can provide high flows over 12 L/min for dynamic activity.

Smart

Smart controllers adapt the pump operation to changes in the patient's activity.

Durable

An anticipated device life of up to 10 years or more.

Small

Small enough for a child, powerful enough for an adult.

Portable

A small external controller and batteries to give patients freedom.

A single moving part

Two centrifugal impellers placed on a single rotor provide perfusion to the left and right sides of the body.

Advantages of a Rotary Pump

Specially designed pump blades allow high flows and low power consumption.

Physiologic Interaction

The device's patented left-right flow-balancing system allows dynamic adaptation to change in the patient's physiology.

Active Magnetic Levitation

Magnetic levitation provides precise, stable operation with no mechanical wear.

Blood Compatibility

Special large gaps within the pump reduce blood cell damage and the risk of clotting.

A patient with an MCS device has an external power source and controller connected to the pump by a skin-crossing cable (a driveline), and these peripheral devices must be carried by the patient continuously.

These patients need careful monitoring and perform numerous tasks which are mandatory for continued safe and independent living.

How does the Artificial Heart Frontiers Program help?

The Artificial Heart Frontiers Program (AHFP) brings together world-leading clinicians, engineers and scientists to develop long-term solutions for all patients with heart failure.

Led by Monash University, the program includes University of New South Wales, Griffith University and University of Queensland – as well as The Alfred hospital, the Baker Heart and Diabetes Institute, and St Vincent's Hospital, Sydney, and major industry partner in BiVACOR.

The AHFP has identified three superior, life-changing devices to address the unmet need of patients with heart failure. These transformative devices will save millions of patients globally, improve their quality of life, increase their productivity, and are anticipated to improve life expectancy.

The BiVACOR Total Artificial Heart (TAH) is a revolutionary, Australian-made, implantable mechanical device, designed to replace the entire function of a failing human heart.

The BiVACOR TAH has world-leading technology, including an optimised hydraulic system to support both sides of the heart; powerful magnetic levitation (MAGLEV) that enhances durability and biocompatibility, with a compact size to support more patients; and automatic flow adaptation that responds to patient requirements without user input.

The BiVACOR TAH provides a platform technology for an advanced Left Ventricular Assist Device (LVAD), a mechanical heart pump that supports the left side of the heart to move blood through the body, supporting the native heart's remaining capability.

The AHFP is also developing a desperately needed MiniPump, which is a miniaturised pumping device specifically designed to support the native heart of patients with Preserved Ejection Fraction (HFpEF), for which there are no other options.

This is achieved by unloading the left atrium and reducing back pressure on the lungs. The MiniPump would offer a unique treatment option for HFpEF, which now accounts for half of all HF cases – nothing of its kind currently exists.

The technology advances being developed in the AHFP are not limited to the three devices – development has commenced on a pipeline of peripheral complementary products: a wearable controller, infection-resistant driveline, Smart Advisor for clinicians, mobile phone application and website for patients, online feedback portal for clinicians, customisable wearables for patients and enhanced surgical

tools and clinical training platforms for surgeons.

Australian healthcare system savings

The AHFP is a game-changing opportunity to deliver solutions for advanced forms of heart failure, as well as deliver substantial health benefits to patients, and economic benefits to Australia.

Development and delivery of AHFP's novel innovations over a 15-year period from 2022 to 2036 is expected to generate at least \$1.8 billion of impact to the Australian economy. This includes savings to the healthcare system, industry expansion in research and manufacturing, creation of jobs and giving Australian patients early access to clinical trials and emerging lifesaving technologies.

Positioning Australia as a global leader

A research grant of \$50 million from the Medical Research Future Fund, announced by Federal Health Minister Mark Butler, will not only help to revolutionise implantable heart devices, thereby addressing unmet patient need; it will also position Australia to be the home of next-generation cardiac devices and peripheral systems.



The BiVacor Total Artificial Heart (TAH). Photo: Supplied



Professor David Kaye

MBBS | PhD | FRACP | FACC

Professor David Kaye is an NHMRC Principal Research Fellow and a Heart Failure/Transplant physician at the Alfred Hospital Melbourne.

Prof Kaye's research has been directed towards the characterisation of the pathophysiology of heart failure, with a particular emphasis on the identification of novel mechanisms that can be targeted for therapeutic intervention. Prof Kaye has been highly successful in the generation of intellectual property leading to commercial and clinical outcomes.

He is an Adjunct Professor at Monash University. He leads the Heart Failure Research laboratory, comprising a number of senior post-docs, RAs, PhD students and BSc(Hons) students.

Prof Kaye is Chair of the Medical Advisory Boards for Opsrey Medical and Cardiora Pty Ltd, both companies which he founded based upon intellectual property he generated.



A/Professor Shaun Gregory

Associate Professor & Deputy Head of Department – Mechanical and Aerospace Engineering, Monash University

A/Prof Gregory has completed Bachelor, Master and PhD degrees in medical engineering at Queensland University of Technology. He then completed his postdoctoral years at the University of Queensland and Griffith University where he was the Innovative Cardiovascular Engineering and Technology Laboratory (ICETLAB) Director for five years and the Chief Technical Officer for De Motu Cordis Pty Ltd (a medication delivery company) for 3 years.

A/Prof Gregory is now the Deputy Head of Department for Mechanical and Aerospace Engineering, the Director of the CardioRespiratory Engineering and Technology Laboratory, Co-Director of the Artificial Heart Frontiers Program, and Academic Director and Founder of the Heart Hackathon international student team competition.

He currently holds fellowships with the NHMRC and Heart Foundation of Australia (Future Leader Fellow). A/Prof Gregory's research focuses on cardiovascular engineering, with a particular interest in the development and evaluation of devices for mechanical circulatory and respiratory support.

By creating a thriving industry of cardiac innovation and investment, the AHFP will be able to respond to future needs by delivering an expert manufacturing base with a nimble, talented group of workers in this growing industry.

Access to AHFP technologies will save millions of lives globally, and improve quality of life and productivity. This will significantly reduce pressure on the Australian and global healthcare system while retaining and further attracting innovators to create a new Australian ecosystem of cardiac innovation - elevating Australia as a global MedTech leader.

If you're interested, you can find more information about this technology at

<https://ahfp.monash/>

News snippets

An Australian breakthrough in the treatment of heart transplant recipients is likely to transform care worldwide

Researchers from the Victor Chang Cardiac Research Institute and Sydney's St Vincent's Hospital have pioneered a non-invasive "virtual biopsy" to replace invasive techniques used to test for organ rejection.

About 100 Australians receive heart transplants each year and routinely undergo from 12-15 surveillance biopsies in the first year post-transplant.

They involve a tube being placed in the jugular vein so surgeons can insert a tool into the heart to remove tissue samples.

"This new virtual biopsy takes less time, is non-invasive, more cost-effective, uses no radiation or contrast agents, and most importantly patients much prefer it," said A/Prof Andrew Jabbour (right).



Running for his life

Dealing with the pressure of Year 12 and running a half marathon to raise awareness about organ donation was nothing compared to what her dad had endured.

By Graeme Klemm and Julie Rogalsky

As a New Year resolution, Alannah Rogalsky, an 18 year old from Traralgon, set herself a personal challenge – to run a half marathon during her final year of secondary school.

Alannah's dad, Shaun was diagnosed with Hypertrophic Cardiomyopathy in May 2011. At the age of 45 he was assessed as being unable to work due to ill health.

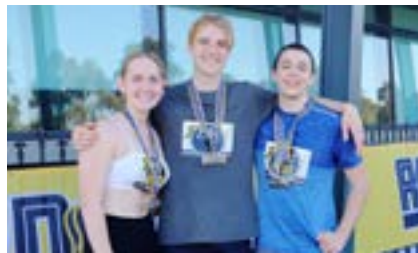
Shaun was forced to retire from his long-term job as a machine operator at Australia Paper where he had worked since he was 19 years of age after starting as an apprentice fitter and turner.

Throughout 2022, Shaun's condition deteriorated to the point that he was in a state of constant heart failure that was creating a number of other complications. He endured 18 hospital stays equating to a quarter of the year in hospital.

On Friday 13 January 2023, he was placed on the Australian Organ Match Authority's heart transplant list run through DonatLife. At the time of publishing, he is still waiting for a call from The Alfred that a heart has become available to him.

Alannah decided to "run for those who can't" namely her dad, and thought it was a good goal during her Year 12 studies as it helped clear her mind while also getting exercise and fresh air.

"Essentially, it forced me to get outside and have a break from study. I set



Alannah with school friends Charlie and Pablo who helped support her to reach her goal.

up Strava to record and monitor my progress."

She started with 5km runs and slowly built on them throughout the year, although she never completed a 21 km half marathon until the actual race!

Alannah ideally wanted to enter the Melbourne Marathon, but it was too close to her first exam so she decided to enter the *Run Prix* which was held on Sunday 24 September at Albert Park.

The day did not start without incident – at 4.30am Shaun woke with complications and needed to go to hospital. He did not see the run as he was still in The Alfred emergency department, but was sent lots of photos and video clips to feel as though he was part of the day and celebrations.

Two good friends from school, Pablo Neofitou and Charlie Blackburn, supported Alannah by also completing the half marathon. All three made the 21 km distance under two hours.

To mark the occasion and raise awareness of organ donation, Alannah thought she would create a

"GoFundraise – running for a cause" page to raise funds for the *Heart and Lung Transplant Trust of Victoria*.

In the end she raised \$5,520 which is an amazing effort for anyone, let alone an 18 year old doing her final year of secondary school study.

Alannah said that she really started to feel it during the last 3 km of the race, but kept thinking of her dad and what he was going through.

She said *"My dad is an inspiration, he never whinges about his condition or how he is feeling when I can tell that he is at times struggling to see light at the end of the tunnel. He is a great dad and used to be so active; working or renovating and building houses in his spare time. I really hope he gets a new heart soon, so he can feel better and so we can do the things we used to do like skiing, walks and holidays."*

Shaun is incredibly proud of Alannah, he was sad that he didn't get to see her complete the half marathon and he thanked family and friends for supporting him and her through donations, love and care.

"Alannah is a beautiful girl on the inside and out, she truly lights up a room. I am extremely proud of how she set her mind to running a half marathon and how much she raised for such a worthy cause. She wants to go to university next year in Melbourne and study Commerce. She has worked so hard this year and shown enormous resilience. Alannah deserves all the good things that come her way."



“My dad is an inspiration, he never whinges about his condition or how he is feeling when I can tell that he is at times struggling to see light at the end of the tunnel. I really hope he gets a new heart soon, so he can feel better and we can do the things we used to do like skiing, walks and holidays.” ALANNAH ROGALSKY



Traralgon teenager and School Captain at St Paul's Anglican Grammar Warragul, Alannah Rogalsky (pictured centre) used the motivation of her dad's heart failure to raise \$5,520 for the Heart & Lung Transplant Trust of Victoria's *Second Chance Accommodation Program* while doing Year 12. What an incredible effort!



SINCE THE ORIGINAL STORY WAS WRITTEN: Shaun received his heart in early December 2023, and is eternally grateful to the donor and their family for giving him a second chance at life. Despite a small setback in late January with a rare infection and subsequent rejection, Shaun now enjoys going to the gym a couple of times a week, visiting the local farmers market, gardening and spending time with friends and family. He is planning on walking the 20km to the Lighthouse at Wilson Promontory National Park later this year to celebrate the gift of life and how far he has come.

I am one of the lucky ones because of the selfless donation heroes

Donors and their families are the true heroes of this world

By **Ross Henkel** | Heart transplant

I am one of the lucky, privileged Donor recipients that are here today because of donor and donor family's generosity.

For mine, they are the true heroes of this world, for their selfless donations, whilst at the same time going through unbelievable grief. Thank you.

My personal journey started around 7-8 years ago when I was diagnosed with 3 Heart Issues. The main issue was a form of Cardiomyopathy which over time would progressively worsen until a Heart Transplant was needed.

At the start I took it in my stride and whilst I would have issues every now and then I lived relatively the same.

Just under 2 years ago I went downhill quicker than the previous years. Taken in an ambulance 4 times and hospitalised 5 times in 4 months was not a quality life, let alone the affect it had on my wife and two boys.

I was still working from home behind a keyboard so I could still do that each day, but I was getting more tired and my concentration was wavering.

When I could, I would go for a walk and walking 2 km was a luxury as the alternate was being out of breath within minutes or falling down vomiting. I just didn't know what each day would bring when I woke up.

Being referred to the Alfred Hospital and going through the testing was an



Ross out on the water enjoying his life post transplant

eye opener as within myself I didn't think I was that bad. However, I failed a few of the tests and had to stay in the hospital for 8 days instead of the usual 4.

I was luckily accepted on to THE LIST.

3 weeks went by, and I was offered a heart. Rushing to the hospital was surreal as we could not believe it was happening.

Unfortunately, just before surgery I was told the donor heart had a disease and couldn't be used.

Whilst I was disappointed, I felt for the Donor family. I still feel for them.

A few weeks later another call, this time everything was a success. I woke up 2.5 days later in the ICU. Around day 8 in hospital I met the transplant surgeon. He said to me that you have a BIG STRONG Heart. I smiled.

After 12 days in total I walked out of the hospital unaided, Thanks to my new BIG STRONG HEART!!

I cannot thank the whole DonatLife Community, Alfred Hospital, Donor Family and the Donor enough for providing me with this gift.

Every day, I pray and give thanks to the Donor and Donor Family.

We have exchanged letters and whilst we may never meet, and they might not be here today, they are, forever in my life and I will treasure every day, every sunset, every smile from my wife and boys because of them.

You have allowed me to support my wife now as she is going through her personal health issues just like she supports me.

My life has started again thanks to MY BIG STRONG HEART.

The emotional roller coaster of being on a transplant list is captured poignantly by Tamara McDonald in her articles in the Geelong Advertiser (opposite page) following Ross Henkel's transplant journey.

Father's anxious wait for gift of life

TAMARA McDONALD

OCEAN Grove dad Ross Hinkal is waiting to receive the 'gift of life' after heart disease caused his health to deteriorate rapidly.

Six years ago, Mr Hinkal was diagnosed with a serious condition that has weakened his heart.

The condition makes it difficult for the heart to pump blood to the rest of the body and can lead to heart failure. Usually before the diagnosis, he became ill and needed general medical attention whenever he felt better.

Later, the 55-year-old father of two adult sons developed postural orthostatic tachycardia syndrome, a condition characterised by a heart rate that is abnormally high when standing.

Mr Hinkal began medication and a few years ago had an ablation procedure to correct the electrical issue.

But his health declined after a further year.

"In December last year, I got another infection and I started to get really sick," he said.

He was unfortunately informed that due to the heart disease, his condition, he had lost 20kg, been in hospital several times and had a stroke.

Mr Hinkal now needs a heart transplant and was placed on a waiting list about a month ago.

Last week, he received a call to say a donor heart had become available at the end of the night.

He travelled from Ocean Grove to Melbourne and was prepared to accept, but was told at the last minute that the heart wasn't suitable.

Mr Hinkal broke down in tears during the process.



Ocean Grove's Ross Hinkal is focused on appreciating the time he waits for a heart transplant. Picture: Mark Wilson

"I wasn't crying because I thought I might die on the operating table. It was just because it was such a relief expression," he said.

"When I was a bit quiet at the time, people were just saying that the heart wasn't suitable."

Mr Hinkal goes by the motto 'move forward, be fit'.

"I can't afford to sit at home and watch TV because I don't know if I'll be lucky enough to be given another transplant phone call," he said.

Mr Hinkal said he was happy to connect with other people facing similar issues.

As he grapples with living

with and looking at the news.

"It's pretty fit and healthy and I could go down to the gym and work," he said.

He said he was happy to connect with other people facing similar issues.

his own mortality. Mr Hinkal is encouraging members of the community to register as organ and tissue donors.

"Please consider it - it is just an opportunity to save lives," he said.

It is important to register as an organ donor as soon as possible.

Transplant recipient 'honoured' by donor's gift



TAMARA McDONALD

OCEAN Grove dad Ross Hinkal has 'honoured' his donor by being granted a second chance at life for an organ donor.

Just six years ago, Mr Hinkal was diagnosed with a condition that has weakened his heart.

The condition makes it difficult for the heart to pump blood to the rest of the body and can lead to heart failure.

In September, Mr Hinkal received a heart transplant, after the disease caused his health to rapidly deteriorate.

The 55-year-old had been

on the waiting list for almost six weeks when he received the donor heart.

In the information he had received, a call at the end of the night and morning from Ocean Grove to Melbourne.

He was prepared for surgery, but was told at the last minute that the heart wasn't suitable.

On the day of the successful transplant a few weeks later, Mr Hinkal was contacted about him and was at the Alfred in Melbourne within two hours.

Feeling 'really excited', he was quickly 'put under' before the procedure, which lasted five to six hours.

Mr Hinkal was then in an induced coma for two days and woke up in the intensive care ward.

He was in ICU for several days before moving to a ward.

Walking just five metres would exhaust him.

Twelve days after the surgery, Mr Hinkal was released from hospital.

He is now attending frequent medical appointments to monitor his body's response to the transplanted organ and it has been adjusting well so far.

"The one unit operation medicine for the rest of my life," he said.

He is taking various medications and is currently on about 100 tablets a week - but it was 200 up until recently.

The father of two adult sons said while he had felt drained in the weeks after the transplant, he was fortunate to have received the heart and was constantly thinking of the family behind the donation.

He now has the energy to stay up all day.

The health is "so much better" after the transplant and he said he was going downhill quickly before it.

"The pain began as early as last year."

He said it had 'definitely' given him a new lease on life and he had likely not had

long left to live with his original heart.

On Tuesday, organ and tissue donors' excitement around Australia will register their gratitude by saying "thank you" to organ donors and their families as part of DonorLife Death Van Day.

Each year thousands of Australians lose an organ and are transferred through the generosity of donors and living organs and tissue donors and their families.

DonorLife signs all Australians to have the opportunity to have the chance to register to become an organ and tissue donor, or check their registration, at donorlife.gov.au.

News snippets

Laser breakthrough in battle against heart attacks

In a game-changer for heart attack prevention, researchers have developed a laser that can detect for the first time who is at immediate risk of a deadly episode.

Tests can see how much plaque has built up in the walls of arteries supplying blood to the heart, but no test can determine if these fatty deposits are at risk of rupturing, regardless of their size.

This is the most common cause of heart attack and coronary heart disease, which remains the No. 1 killer of Australians.

But by using near infra-red light, cardiac researchers from the Baker Heart and Diabetes Institute in Melbourne and optical physicists from Melbourne's Swinburne University have developed a prototype laser that is threaded up to the heart through an artery in the groin, like a standard angiogram.

Under the light, any unstable plaques become visible for the first time, appearing fluorescent and revealing who is at risk of heart attack in the preceding hours, days or months.

Lead researcher Karlheinz Peter said being able to detect who needed immediate treatment to prevent heart attack was "the holy grail of cardiology," and he hoped his device could save millions of lives each year.

"This is something patients are often disappointed about with cardiologists, that we can't foresee if they will develop a heart attack."

Their decade of research has been funded by federal government grants, getting the project to the stage where patents have been granted in the US and Japan. Now the researchers have started a medtech company called Nirtek to develop the prototype and raise the \$6 million needed for the first large scale clinical trial in heart attack survivors.

By Brigid O'Connell

The Advertiser, Monday February 8, 2021



ROCKMANS APARTMENTS



There's a new way to stay in a city *...live like a local!*

Rockmans Serviced Apartments in South Yarra presents luxury accommodation ideally located for an effortless commute to Melbourne CBD and on the doorstep of Chapel Street's cultural hub.

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

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

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



Your host
Robert Rockman



Rockmans Apartments
1 Moffat Street, South Yarra, VIC 3141
Tel: 0481 10 10 10
info@rockmansapartments.com.au

www.rockmansapartments.com.au

ACCOMMODATION PARTNER OF THE HLTTV



ROCKMANS APARTMENTS

This stunning premier building of 13 apartments with secure swipe entrance offers bright and spacious one and two bedroom apartments. Exquisitely decorated and furnished to the highest standard the apartments are installed with boutique features such as home entertainment system, open plan kitchen and comprehensive utility services.



Residents can also enjoy the landscaped garden with outdoor BBQ area, Australian ash timber ceilings, off street parking as well as optional private gardens, for a 'home away from home' atmosphere or a comfortable corporate retreat. Plush furniture will guarantee your comfort and the memory foam mattress will allow for an excellent sleep.



Comfort and security

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

Kitchen

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

www.rockmansapartments.com.au

ACCOMMODATION PARTNER OF THE HLTTV



Photo: Peter Adams

Unbreakable Glass

A story of unwavering belief in a boy that refused to succumb to the inevitable

By Graeme Klemm and Cindy Glass | Cindy's son *David* had a heart transplant

Despite being born just 3 minutes before midnight on St Patrick's Day, his parents (one of them of Irish descent) named him David 'Hope' as they were already well aware of the significant challenges he was about to face.

Given the opportunity to terminate him during pregnancy on very considered medical advice, David's parents Cindy and Liam Glass, both of whom had individually faced their own hardships in life, were adamant that their first child together would be given his chance in the world and they would face whatever came next head-on with him.

Whether you believe in fate or faith, this story will at least pose the possibility that this little boy was destined to be born with just the right parents to give him a chance to survive.

There could be no room for doubt, no hesitation in the face of insurmountable odds. He needed them to bring all of their own determination, resilience and strength to the fight for his life. He needed them to be unwavering.

I originally visited the Glass family, now four of them with the addition of Bella, at their home in Morphett Vale, 30km south of Adelaide. Like many families, they celebrate their kids with photos and memories scattered around. What struck me immediately was the warmth of the welcome. This was a house with love and care and the ensuing four hours flew by as we shared our transplant stories and experiences.

Even though we share the same transplant year, 2019 and there's

well over 50 years between us, the experience shares many points of commonality, not only between us, but many others who share the journey – fluid overload, ECMO, life support, struggle, emotional and financial toll on our families.

I recently visited the Glass family again to say hello and see how David is going with his new heart. What I came away feeling was a deep respect for a family that have stared down the bleakest and most emotionally draining experience and come out the other side with everything to look forward to. A wonderful, loving family with a significant story to tell.

Here is Cindy's account of the journey they have been on...

On 15th October 2015, Liam and I went for our 20 weeks' pregnancy scan to see our first born.

We were excited but the person doing the ultrasound was very cold. We were asked to go for a coffee and come back later.

A cardiologist was present the second time and invited us into a counseling room. Our world then turned upside down.

We were told David, our first born, had congenital heart defects, described to us as a single ventricle, crossed arteries, holes in the heart, ASD, AVSD, with everything formed on the right side.

They couldn't see eyes at that stage and said they were suspecting



A younger David with his little sister, Bella

Article continues on following page...



David (front right) with his dad Liam, mum Cindy and sister Bella

DeGeorge Syndrome, Mal bowel rotation and no spleen.

I felt extreme pressure to terminate my baby and was receiving phone calls every second day to come in for an abortion.

I broke down in tears, feeling sick and unable to digest this painful news. We had no family and support in Australia. It was so hard that we lay in bed for days crying, praying and processing the news.

Miraculously, and thankfully, David was born with only the complex heart defects.

At four months of age David was scheduled for his first open heart surgery to insert a shunt and let oxygen flow to the left side.

Unfortunately, they discovered a leaky valve and the whole plan changed as David wasn't going to qualify for a Fontan procedure later in life.

David always had low saturation 75 to 80%. At 18 months we were sent for a second open heart surgery to fix the

leakage. After the surgery was finished and the drains were removed we were told that the surgery was unsuccessful.

I was pregnant at the time and feeling unwell, so hearing bad news again was very hard to digest.

Six months later, and with a two weeks old newborn baby, we went to the hospital again to fix the leakage (David's third open heart surgery).

After opening David's chest, they couldn't fix the leak and decided to replace it with a mechanical valve.

Unfortunately, a nerve was hit during surgery and David's heart went into complete heart block, so they had to close his chest and connect an external pacemaker.

Only one person in the hospital knew how to operate that external pacemaker at the time and David went into cardiac arrest twice.

After six days and with the heart block not resolving, David had to go for a fourth open heart surgery to insert a permanent pacemaker.

They started talking about a heart transplant but we were not ready emotionally at that stage to hear about and accept that another child needed to pass away and become a heart donor for David to get a new heart.

Our newborn was 10 weeks old with David in hospital and I was completely drained. I'd had enough and remember saying "how much is too much God and was reminded to be still and trust".

David got pneumonia, sepsis and was canulated in both arms for five hours on Morphine. We were given notice that the 24 hours were going to be critical as he was drifting between life and death.

David fought hard, but we got very anxious. It was actually traumatising to go through.

All we wanted was to get both kids home and safe, so we steeled ourselves and David continued to fight hard for himself and we got home for Christmas 2018.

In March 2019 David got very sick and it was not easy to get in to see his doctor. We presented a few times at Emergency but they said he was fine. I was sure he was in heart failure but they kept sending me away.

After nearly begging for three weeks, we finally got an appointment to see a Cardiologist.

It was a Thursday afternoon when we went to that Cardiology appointment. After doing David's heart ultrasound, everyone in clinic start rushing around and we could feel the tension and panic in the room.

I knew straight away there was bad news coming our way.

The Cardiologist told us that David's heart was not even squeezing and that we had only 48 hours before David would pass away.

OMG! I was so angry and scared. I felt absolutely sick, my stomach was churning and tight.

Why had nobody listened to me!

David was sent to ICU to start a drug called Milrinone to support his heart function. Doctors were expecting him to die at any time and a priest was brought in to bless David.

After nearly a week David was still in ICU. The doctor who assisted with David's admission advocated on our behalf and got the Flying Doctor Service to medi-vac David to Melbourne's Children's Hospital.

David stayed on Milrinone for about a month in Melbourne with little sign of improvement. It was clearly visible that all of his organs started to shut down.

The hospital called a meeting to discuss the fact that they found the pacemaker in David's body was faulty, but there was an option of removing the existing pacemaker and attaching a more advanced model to squeeze both atrium and ventricle.

This option would give David time to wait on the transplant list. We were told this surgery would be high risk though and there was an 85% risk of David going to sleep forever after been put under anesthetics.

The entire team disagreed with this surgery except for one surgeon who said that he was willing to perform the procedure if Liam and I wanted to give it a try. We were grateful and felt at peace to go ahead with the surgery. We just wanted our little boy to get the help he needed to survive until a heart became available.

So one morning in June 2019, the anesthetist met us in a real mess – red eyed and teary. Everyone was very sad knowing the potential outcome of David's fifth open heart surgery.

Leaving David in theatre was different that time, we were told to stay in the room whilst the surgeon briefed his team: *"Today there will be no bypass machine, there is an 85% chance David would pass while he is asleep, but we*

will keep going with the change of pacemaker, close his chest and call the parents to say goodbye. We will not resuscitate David and there will be no life support machine for him. If anyone doesn't feel comfortable they can leave now."

Tears rolled down the nurses' cheeks but they all stayed. We still believed GOD WOULD HAVE THE FINAL SAY.

The surgery went on for five and a half hours. We were so nervous, waiting for that call. The surgeon did finally call, asking us where we were so that he could come to us.

Still in all his surgical gear, the surgeon ran to us along the corridor saying *"David's heart didn't flinch and he is ALIVE."*

We hugged the surgeon and cried. The adrenaline was running through our bodies. The surgeon agreed with us that God was present and David's recovery was so good that he was listed for a heart transplant that day.

A few weeks after being listed, we received a call during the night to say *"Mr. Glass we found a heart for David."* Liam dropped on the floor, his legs went like jelly.

It was a better feeling than winning the lottery.

We made our way to the hospital and David wanted to go to theatre by himself. He said he was ready and could put the mask on to go to sleep by himself.

It was a long surgery and we got to see David in ICU around 8pm that night. David's recovery was very smooth and he has gone from strength to strength ever since the transplant.

We are forever grateful to donor families during their hardest time making these selfless decisions.

No words can describe that bittersweet feeling. Organ donation has made a huge impact on our life.

David got a second chance at life. Hats off to the hospitals, doctors, nurses, surgeons and all the essential workers.

We are all human and mistakes can happen but we had to fight very hard to keep David alive through the hardest times, particularly those crucial 48 hours during the pacemaker change-over. It may have been easier and safer surgery had we been listened to earlier.

As David's parents, Liam and I will never stop advocating for him.



To honour the transplant community, Liam Glass has created an annual fun run/walk event called 'Run for Hope' (in celebration of his son David Hope Glass) in his local community to raise attention about transplant and organ donation.



Photo: Peter Adams

The artificial heart set to transform medicine – and the Aussie who invented it

Biomedical engineer Daniel Timms lost his father to heart disease, but their kitchen-top tests helped him hone a radical idea.

By Amanda Hooton | GOOD WEEKEND – *The Sydney Morning Herald*, April 20, 2024

One day this may be one of those eureka stories everybody knows, like Newton and his apple; Fleming and his Petri dish; the Wright brothers and their aeroplane. Daniel and his dad’s plumbing. Because that’s where Daniel Timms’ BiVacor total artificial heart began: in a backyard in Ferny Hills, Brisbane, filled with ponds and water fountains, built on the weekends by a small blond-haired boy and his dad, a plumber.

There’s a picture of the pair from this time: one of those old, amber-toned images that is, somehow, intensely moving. Timms is two years old, sitting beside what appears to be an irrigation trench, his little body intently focused on the tall figure of his father. Gary Timms is crouching in front of his son, long fingers screwing something together. Look at this, mate. *Can you see? This is how you do it.*

Twenty years later, in 2001, Gary Timms, at just 50, had a heart attack. He survived, but in the aftermath, his son realised two things. One: his father’s heart was irrevocably damaged. Heart failure can take years to kill a person, but eventually Gary’s labouring, leaking heart would stop, and he would die. And two: perhaps he, Daniel Timms, by then a PhD student in

biomedical engineering, could build a new heart to save him.

Almost every day since, Daniel Timms has been working on this heart. In the early years, Gary helped him. Together they made a model of the human circulatory system out of pipes from Bunnings. As Timms has explained it, they’d go to the store on weekends, sit on the floor in the plumbing aisle, and connect bits and pieces while interested bystanders stopped to ask questions, which the duo answered by saying they were building a fish tank. (If they told the truth, people got

too interested, and Daniel Timms – an intensely non-attention-seeking sort of person – found it too, well, attention-creating.) Then they’d take their selected pipes and valves and U-bends home and add them to the rig they’d set up on the kitchen bench. Timms’ mum Karen, a high-school science assistant, had to manoeuvre around it to get to the oven.

That was more than 20 years ago. Today, a burnished titanium device that carries the visible DNA of those kitchen-bench days is about to be implanted in a human. It may have



Daniel Timms, aged two, watching his plumber dad Gary in their suburban Brisbane backyard. *Courtesy of Daniel Timms*

already happened by the time you read this story. And if it works as many of the world's foremost experts believe it will, the plumber's son will have rewritten medical history.

Heart disease is the biggest killer on earth. And heart failure, in which the heart doesn't pump enough blood to supply the body's needs, affects more than 64 million people globally, including as many as 500,000 Australians. About 60,000 Australians are newly diagnosed with heart failure each year, and more than 1500 people are hospitalised every day. In this country, according to the Heart Foundation, on average, one person dies of heart failure every three hours.

In the US, it's estimated that 100,000 patients are in immediate need of either a VAD (a ventricular assist device, useful if only one side of the heart needs help) or a total heart transplant. In Australia, the numbers are much smaller – in the hundreds – but wherever you are, the outlook for severe heart failure is bleak. Drug therapy is limited, and though heart transplant is the gold-standard treatment, donor hearts are few and far between: only about 5000 become available globally each year.

Even if you're lucky enough to get one, heart transplant itself is no picnic. Recipients must take a daily cocktail of drugs, including powerful immunosuppressants, which are toxic. They make you vulnerable to infection, they can contribute to illnesses including cancer, and they are a significant part of the reason that heart transplant has only a 50 per cent survival rate after 10 years. You can have a second transplant, but then the odds are even worse.

"That's why doctors are very cautious about doing a transplant in young patients," Daniel Timms will tell me. "As one doctor said to me, 'I know that if I do a transplant on a young kid, I'm consigning them to an early death.'



Haskell Karp, recipient of the first artificial heart implant, the Liotta-Cooley heart, recovering from surgery in 1969. Previously, the device had only been tested on seven animals. Karp survived 64 hours until a human heart transplant became available, but died 32 hours later. *Photo: Getty Images*



The Liotta-Cooley heart was the first completely artificial heart implanted into a human being. *Photo: Getty Images*

But at this point, there's nothing else you can do."

This, in a nutshell, is the point of a total artificial heart. To develop something that doesn't set up a storm of defensive reactions in the body that ends only with death; to offer patients something other than a life dependent on drugs, vigilance and luck.

Timms himself sometimes likens the artificial heart dream to the race to put a man on the moon. In the heady optimism of John F. Kennedy's 1960s

America, both dreams seemed well within the grasp of science. And indeed, the moon landing – on the face of it the more complex undertaking, filled with potential catastrophe – occurred, relatively speaking, both swiftly and with little loss of life. It was the heart that remained recalcitrant, as hearts so often do. More than 50 years after Neil Armstrong first walked on the moon, humans have yet to build a successful artificial heart.

The first attempt was made (like the moon landing) in 1969, in the unlikely city of Houston, Texas. For the previous decade, two American cardiac specialists, Dr Denton Cooley and his boss Dr Michael DeBakey, had been frontrunners in the artificial-heart race. One Friday in early April 1969, when DeBakey was out of town for the weekend, Cooley persuaded one of DeBakey's young surgeons, Domingo Liotta, to use the artificial heart Liotta had been developing under DeBakey's supervision. Using an operating theatre at the Texas Heart Institute (now one of the world's leading cardiac treatment and research centres), they implanted it into a 47-year-old man called Haskell Karp.

This heart was air-powered, connected by plastic hoses to a controller the size of a chest freezer, and made of two small chambers of rubbery plastic. It looked like a pair of very small bellows: the kind of thing you'd use to stir up a goblin campfire. As a device, it was virtually untested: it had only been trialed in seven animals, and four of them had died on the operating table. Haskell Karp survived for 64 hours, long enough to receive a human heart transplant. He died 32 hours later of kidney failure and pneumonia.

Dr William (Billy) Cohn is an internationally renowned heart surgeon, device-deviser and present-day artificial-heart-Daniel-Timms-evangelist at The Texas Heart Institute. After that first operation, Cohn explained during a presentation in Texas recently, *"For the next 40 years [DeBakey and Cooley] didn't speak. They were in hospitals separated by a car park, and they became the two busiest heart surgeons in the world – in the 1980s, their combined programs performed more heart surgery than was done in all of Europe. And they didn't speak."*

In the world of artificial hearts, the practical and ethical issues that

caused this feud still exist today. Is such surgery outrageously hubristic or a valiant attempt to preserve life? None of the devices designed since 1969 – including the SynCardia, the AbioCor, the Carmat – have proven that life with an artificial heart is viable long-term. Some patients have survived for months, and in very rare cases, years. But all artificial hearts to date have been used temporarily, as bridge-to-transplant devices. And sometimes – often – their recipients have died before reaching this goal.

Why have these devices failed? Let us count the ways. Traditionally, artificial hearts have been based on Mother Nature's version, with its chambers and valves – which means they've had multiple moving parts. They've been pulsatile – pumping blood in pulses, just as the heart does. They've been large: too big for most women, and all children. All of them (bar the AbioCor, which was abandoned after \$US250 million of investment when all 14 of its trial patients died) have had permanent drivelines, powering and controlling the heart from an external box – the controller – that must be worn 24/7.

Perhaps unsurprisingly, all have had basically the same set of problems.

Every artificial heart so far has caused blood clots, which kill patients. All have made their recipients vulnerable to infections, especially through the drivelines, which kill patients. Their size has rendered them essentially useless to more than half the world's population. And most fundamentally of all, they've ultimately failed to do the one apparently simple – in fact, profoundly difficult – thing a heart is designed to do: keep pumping.

The human heart beats, on average, just over once a second. That's about 70 beats a minute, 100,000 times a day, 37 million beats a year. No man-made device on earth has ever come close to matching that.

Until now.

Maybe.

Today, in the offices of Daniel Timms' company, BiVacor, in Huntington Beach, California, several artificial hearts are pumping. (Timms has been based largely in the US for more than a decade.) These BiVacor hearts are nothing like the human heart. They do not have chambers. In their base mode, they are not pulsatile – which means a person implanted with one would have no pulse. They have no valves and only a single moving part. They are heavy (about 650 grams) but small – small enough for some children and virtually all women. In animals, they cause far fewer blood clots than any previous artificial heart; so few that several animals implanted with them have not required blood-thinning medication. They intrinsically adjust to changes in blood flow, exertion and position when they are inside a living body. They do have drivelines and a controller, both of which Timms hates. But they also have something else. So far at least, they have an unblemished ability to keep on pumping.

"We've got eight of these, two years on, without a failure," Billy Cohn, now chief medical officer of BiVacor, explained during his presentation, his drawl even



Renowned heart surgeon Billy Cohn, now BiVacor's chief medical officer: "This thing will pump until the Earth spirals into the sun!" *Photo: Google Image*

Article continues on following page...

more pronounced than usual in his excitement. *"We have one pump that's been pumping for five years. This thing will pump until the Earth spirals into the sun!"*

Australians, it seems fair to say, are slightly more understated than Americans – and Daniel Timms is understated even for an Australian. Indeed, he's so quietly self-effacing that when I interview him, I spend our entire conversation in an agony of apprehension that my tape recorder won't pick up a word he says.

It's also true that, historically, this understatement has not always served us well when it comes to world-changing technology. The phrase *"punching above our weight"* comes up several times during my research for this story, and it's used, each time, to describe our national ability to come up with cool stuff in the fields of science and medicine: the CPAP machine to treat sleep apnea; Wi-Fi; the human papillomavirus vaccine; the solar cell. But then, when it comes to manufacturing, selling and profiting from our innovations, another phrase appears: some variant of "now made and sold overseas".

According to conventional wisdom, Australia simply doesn't have the cash to fund the massive costs of bringing biotech *"off the bench"*, as University of NSW biomedical engineer Dr Michael Stevens puts it, through development and trials. Nor do we have the specialised manufacturing infrastructure to actually make things here. Instead, we export our intellect the way we do our mining and agricultural products – as a primary product, to be refined, manufactured, marketed and profited from overseas.

But recently, the federal government has taken steps which might disrupt that story. In February (a month before its announcement about investment in domestic solar cell manufacturing, as it happens), the Medical Research



Dr Paul Jansz is set to perform St Vincent's Hospital Sydney's first BiVacor implant, which he describes as "the Mars expedition." Photo: Kate Geraghty

Future Fund awarded \$50 million to a single, multifaceted Australian biotech initiative: the Artificial Heart Frontiers Program (AHFP) for the development of devices to assist failing hearts.

A multidisciplinary consortium led by Melbourne's Monash University but based all around the country, the program's remit is partly to do research, but there's also an explicit goal to *"seed an entirely new Australian specialised industry"*, as the website puts it. In other words, to patent, manufacture and market locally invented, globally relevant heart-device technologies. *"It's a whole ecosystem," says cardiologist Professor David Kaye from Monash, who is one of the co-leads on the program. "If you look around the world, I can't think of another program like this – engineers and clinicians working together, with proper funding, governance, structure."*

Carolyn Stone, the program's chief of operations, hopes it addresses the often siloed nature of research. *"Everyone's incredibly good at their thing," she explains. "The key to getting something to market is that you've got to bring all the pieces together. It's not just having brilliant people in the*

lab, you've then got to have experts to take it to clinical trials; people for development; people to get it into production and to the market. That's the big challenge."

To solve it, the AHFP has gathered what it hopes is an Avengers-style team of experts. As well as nationally recognised cardiologists David Kaye and Professor Christopher Hayward from St Vincent's Hospital Sydney, there are people such as Griffith University associate professor Michael Simmonds, an expert on the way blood responds when it flows through man-made materials instead of living tissue. And University of Queensland professor Cara Wrigley, who understands that patients living with external controllers still need to take showers and get through airport security without their electronics shorting out or setting off a bomb alarm. And authorities like UNSW professor Nigel Lovell, who creates remote patient-monitoring platforms, and Dr Michael Stevens, who researches physiological control systems for cardiac devices; and Monash professor David McGiffin, who's investigating driveline infections

and mini-pumps. There's even Daniel Timms: BiVacor is one of the program's flagship devices – it will receive \$17.5 million of the \$50 million total. This money will support the clinical studies of Timms' heart; a ventricular assist device BiVacor also has in development; and various technologies that will support both. It's hoped, for instance, that some components of the BiVacor heart will be made in Australia.

Nothing like the AHFP existed when Timms started out, of course. But ironically, many of the people who are now part of it – professionals with distinguished careers and international reputations – have worked on BiVacor over the years, often as students, drawn in by Timms' ability to attract other people as crazily committed as he is.

Professor Shaun Gregory, for example, met Timms when he was a teenage undergraduate in Queensland; Timms was his PhD supervisor. Today, he's co-director of the AHFP and director of the Centre for Biomedical Technologies at Queensland University of Technology, as well as the president-elect of the International Society for Mechanical Circulatory Support. *"If you want to call*

us 'The Avengers fighting the common enemy of heart failure,'" he says, *"that's OK."*

John Fraser, one suspects, would don a superhero suit in a heartbeat. He is now, among other things, the director of ICU at St Andrew's War Memorial Hospital in Brisbane, but he first encountered Daniel Timms two decades ago at Brisbane's The Prince Charles Hospital as a young intensive-care doctor. Sitting in his research office one day, he suddenly noticed an annoying *plip-plop, plip-plop* coming from next door.

"Eventually I went to have it out with the weirdo making the noise, and there was Daniel with his Bunnings pipes all over the bench," Fraser recalls. *"I said, 'What's this?' And he said, 'It's how a heart works.' And I said, 'Umm, not really.'"*

Before long, however, Fraser was a convert to what Billy Cohn in Texas has called *"the cult of Daniel Timms"*. Today, he points out that he hasn't had anything to do with BiVacor (which he and Timms co-founded in 2008) for *"years and years"*. But back in the day, Fraser helped Timms – who'd been

given a stipend and a single room for research at Prince Charles while still a PhD student – with access to the institutions and networks of medicine. Today, those early years sound like a cross between a *Boy's Own* adventure story and *Spinal Tap*: all Brisvegas barbecues and devices wrapped in protective underpants and surgeons banging tables and telling our heroes that pulseless hearts will never work.

The heart Timms was working on was closely based on the one he'd first conceived as a student: a single spinning disc inside a metal casing that pushed blood through the body not in pulses, like a natural heart, but in a single continuous flow, like a plumbing pump. He and his dad had built a rough prototype (Gary Timms had machined the central disc on a mini lathe he'd set up next to the TV) and tested it on their kitchen bench circulatory system. And it had worked, pushing water filled with tiny beads (representing red blood cells) around the system.

But as Timms told *The New Yorker* in 2021, they also noticed beads getting stuck in an eddy under the disc. In the real world, this was a danger signal. Points of slow flow, in blood, are points where clots might develop. And clots can lead to strokes – the great bane of all artificial hearts.

Timms reached out to a Japanese researcher working in magnetic levitation – the process by which Maglev trains work. He had no money to pay for advice, so he went to Japan and worked on the researcher's own project in exchange for help. He would do this again and again in the coming years, travelling to Germany, Taiwan, the US, wherever the experts he needed were based. And slowly, over years and years, he built a heart.

Today, the BiVacor total artificial heart consists of a single titanium chamber with one moving part: a spinning disc (called the impeller) floating inside the casing. Because it's suspended



Professor Shaun Gregory, director of the Centre for Biomedical Technologies at Queensland University of Technology: *"If you want to call us 'The Avengers fightin the common enemy of heart failure'... that's OK."* Photo: Google Image

Article continues on following page...



Professor John Fraser first encountered Daniel Timms two decades ago at Brisbane's The Prince Charles Hospital. Photo: Supplied

by Maglev technology (thank you, Japanese researchers), wear and tear is eliminated. This impeller simultaneously pumps blood to both the lungs and the body, because it has vanes poking out on both sides – high on one side, like prongs on a barbecue fork, low on the other, like the blades of a fan. These prongs drive the blood first gently into the lungs, then powerfully into the body.

Thanks to this design, the BiVacor has much larger spaces for the blood to flow than other artificial hearts – which means there's fewer places for clots to form, and less likelihood of blood cells being “*smashed up*” (the technical term) by the mechanism itself. Some blood does leak around the edges of the floating disc but this, according to key engineers on the project, is “*a design feature, not a bug. The wash of blood around the disk [sic] cleans out the casing and ensures there are no areas where stagnant blood can form into dangerous clots.*”

Today's BiVacor heart also has a pulse. It's still not really understood what, if any, advantages there are to pulsatile blood flow in the body; and Timms the engineer seems sceptical about

its necessity. But nonetheless, a few years ago it became clear they could create a BiVacor pulse simply by rapidly alternating the disc between high and low speeds. Was it done just to, well, placate doctors? “Precisely.” Timms smiles. “*There may be some advantages, there may not. But we can do it, so we thought, 'Why not? We can always turn it off.'*”

The BiVacor heart can also do something else. It continuously adapts its output to match a patient's daily life. Our biological hearts are constantly adjusting as our bodies sit, stand, go to the loo, climb the stairs, jog. The BiVacor's spinning disc can do a version of the same thing, moving along its central axis from left to right. This movement changes the efficiencies of the two sides of the disc, pumping more blood through the lungs and out to the body as we exercise, less as we sit reading a weekend magazine. No other artificial heart has ever been able to adjust to the living human body in this way.

So. Could this heart be the Holy Grail of cardiac medicine: a permanent artificial heart? Titanium is biologically inert: no immunosuppressants

required. One moving part: no wear and tear. A pulse – if required. The potential to intrinsically adjust blood flow to daily life. In Timms' heart of hearts (ahem) there seems little doubt. This, he believes, is the heart that will revolutionise current transplant survival rates. This is the heart that will work – forever.

“I was talking to a doctor at the paediatric hospital in Texas,” he explains. “He wanted to do a study with us. And I was like, ‘But it's not a paediatric device: it's too big for a toddler.’ And he goes, ‘Daniel, I don't want it for a four-year-old. I want to put the transplant heart in a kid at four and I want them to grow up to be 12. And then I want to give them the BiVacor for the rest of their life.’”

Speaking of life. Back in 2004, a year or two after Daniel Timms talked to the Japanese, his dad Gary needed a heart valve replaced at The Prince Charles Hospital. By this point, Timms had his stipend and his research room at the same hospital, and he'd go and visit Gary on his breaks. John Fraser remembers Timms being at the hospital night and day, no holidays, no weekends; eating two-minute noodles and sleeping on the couch Fraser had bought him.

All the while, time was running out. Timms has subsequently said that he knew, realistically, that his artificial heart would never be ready in time to save his dad. But faced with the prospect of losing him, he couldn't help but try; couldn't help but hope. The heart has its reasons which reason knows not, after all.

In 2006, Timms implanted his device into a sheep, showing it was workable. Soon afterwards, Gary became very ill. Timms was about to go to Europe to talk to pump engineers in Germany. As he told *Forbes* magazine, he asked his dad if he should go. “*You've got to get there,*” said Gary Timms. “*This is what we've been working for.*”

John Fraser, the intensive care specialist, still remembers the next two weeks. *"I brought Gary from the wards to ICU so I could look after him personally, and I was phoning Dan on a daily basis."* Gary grew worse and worse. When the end was close, Timms flew home, but by the time he arrived his dad had a tracheotomy tube and was heavily medicated. And so there were no last words between father and son about hearts, mechanical or otherwise.

After Gary Timms' death in 2006, aged just 55, his son kept working. And working. And working. "Daniel is someone who is brilliant, and someone who is incredibly stubborn and pigheaded," says Fraser. *"I mean that as a compliment. There are people with good ideas who have come and gone, and Daniel has had one vision and he's kept going."*

Stubborn pigheadedness has no doubt driven him. But so has love.

In November last year, BiVacor received approval from the US Food and Drug Administration (FDA) to implant its artificial heart into three patients. Today, in March, sitting in the cafe at St Vincent's Hospital Sydney in jeans and trainers, Daniel Timms reckons the first implantation is *"probably three weeks away – maybe a month"*. This means that by the time you're reading this story, it will either have already happened, or be just about to. The first implant will be at the Texas Heart Institute, the same place the world's first artificial-heart operation was performed 55 years ago, and where Timms, now 45, seems to be regarded as a kind of beloved, albeit slightly odd, Aussie wunderkind.

Still, when we meet, Timms doesn't seem like a man crazed with excitement at the achievement of his lifelong dream. Despite his terrifyingly quiet voice, he's articulate and funny – but he's also self-contained, unusually focused and intent. Somewhere, not

terribly far away, is still that small boy, watching and learning in a Brisbane backyard.

Rather prosaically, he's back in Australia because he has to renew his US visa. American optimism, capital and appetite for risk has allowed him to refine BiVacor's design in the past decade; to test it in live animals (an emotionally challenging part of cardiac device development); and to work towards the moment it can finally be placed in a person. This moment, in other words. As he told *The New Yorker*, this project has consumed his life. He hasn't married or had children: *"I've been stuck on this."*

And of course, the work isn't over yet. Unless there's some catastrophe in the US trial, and pending Australian ethics approval, the BiVacor heart will not only be implanted into Americans this year, but also a handful of Australians. In both countries, the operations will be part of a *"first-in-human"* early feasibility study, and the BiVacor hearts will only be used until human donor hearts become available for transplant. Status as a permanent replacement heart is still an unknown distance away – perhaps until the BiVacor device simply functions so well that there's no need to replace it.

Of course, there's no guarantee it will work. Human blood, for instance, is different to that of cows and sheep, the animals the heart has been tested in: perhaps the BiVacor heart will cause some unexpected haematological reaction or damage in humans. Perhaps there will be some unforeseen reaction in the body to the device's particular design, or its positioning, or the external controller. Perhaps it will, for some reason, just stop pumping. Nobody I speak to anticipates these things, but this is life – and heart design – after all. Unexpected things happen.

Timms is clearly not expecting disaster, though he is anxious. *"For the core team, yes, it's an anxious period,"* he

says. But he's also focused on the next step. *"Once this study is done, all being well, we'll scale up the production, and we can do a clinical trial. And that might be 50 patients. And then we're on the market and ready to sell."* He gives a half-laugh. *"Because if it works, it works. You can't hide with this sort of thing."*

"This is the Mars expedition," explains Dr Paul Jansz, head of the mechanical circulatory assist program at St Vincent's, who's set to perform the first BiVacor implant in Sydney. Melbourne's The Alfred hospital will also be part of the Australian BiVacor trial. *"There's a quantum leap with this sort of technology, because you're cutting the heart out. So there's a 'gulp' moment where out comes the heart and in goes a device that you hope's going to work."*

Of course we cut hearts out all the time when we do transplants, but we know we've got another one to put in. So there'll be a certain leap of faith when we do one of these."

Jansz has performed a number of first implants of devices. *"And there are always a lot of nervous engineers, a lot of people in the room. I'm sure Daniel will be there, going, 'Oh, can you check that stitch?'"*

"I would never say that," grins Timms. Still, you can't help thinking he'll be more comfortable when this period is over, and he can start the next phase: making the device even better.

Getting rid of the drivelines is a particular priority. *"We're going to take the electronics in the power box [controller], miniaturise them, and put them actually in on the [device],"* he explains. *"Then we can remove the driveline, and transfer power across the skin, like charging an iPhone."* He sits back.

"And then the patient won't have a wire breaking the skin; then they can take off the power box and be more active and free."

Article continues on following page...



Sydney heart transplant candidate Ray Meneses thinks he would take a perfected artificial model. Photo: Walter Peeters

I think of the man I met yesterday, a 45-year-old father of three from Liverpool in western Sydney, Ray Meneses. Eight years ago, his heart suddenly began to fail: in 12 hours he went from the GP, where he'd gone to discuss feeling breathless, to St Vincent's emergency, where he was told he would need a heart transplant. During the work-up to go on the list, doctors discovered he had cancer – lymphoma – under one arm. No one can receive a transplant while having chemotherapy; nor could Meneses be placed on the list until he'd been in remission for four years. He survived cancer; four years later, he went on the list. He waited almost another four years. In the meantime, he had an LVAD (left ventricular assistance device) implanted to help his heart pump – he sits with the controller on his lap while we talk.

This Australia Day, at last, St Vincent's called: they had a donor heart for him. The happy end to this long, harrowing story, one thinks. No. When they called, Meneses had COVID-19 and was taking antivirals. And so he wasn't eligible for the heart.

After he tells me his story, we sit in the uncomfortable hospital chairs for

a while. I tell him about the BiVacor device. In a perfect world, if it was available – with no drivelines, no controller, just the man-made version of six million years of evolution – would he take it? Or would he keep holding on for a human heart? Meneses – who appears to be an extraordinarily sanguine, hopeful person – thinks about it for a long moment.

"I think I would take it," he says finally, seriously. "I would take the artificial heart. I have waited so long."

At the end of our interview, I ask Daniel Timms if his dad's heart condition makes him, Daniel, more likely to have problems with his own heart. *"Probably," he smiles. "When we first got to Texas Heart, Dr Cooley was still around – the guy who did the very first artificial heart transplant. And someone once asked him, 'So, Dr Cooley, you are the most prominent heart failure specialist in the world. What can each of us do, ourselves, to prevent heart failure?' And he said, 'Change your parents.'" Timms laughs, shaking his head. "That was his answer."*

There is no doubt the tragedy of Gary Timms' early death changed the course of his son's life. But as Timms

points out, there's nothing unusual in that. *"It's like, Mum's incredibly proud of what we've done. But every time there's a news story or something, what she says is, 'Your dad must be really proud.' It always comes back to that. She's been by herself now for 20-odd years. And I imagine, a lot, what it would have been like if he'd been around for those years. It would have been a totally different life for me, my mum, my brother, everybody."*

He pauses. *"People think it's the patients that are benefiting the most from this technology. They're not. It's the family that's benefiting most."*

The toddler in the backyard, the PhD student, the history-making engineer – all of them potentially free, in another life, of this particular form of heartbreak.

Would the BiVacor heart have saved Gary Timms? *"Once his valve started to fail?" asks Daniel Timms, with a crooked smile. "That would be a perfect application."*



Photo: Nic Walker

Amanda Hooton

Amanda is an Australian journalist and columnist and a senior writer with Good Weekend. Her work has appeared in the Sydney Morning Herald and The Age. "Good Weekend" Magazine is a supplement that is distributed with those newspapers.

She has also provided articles and worked for Stuff.co.nz, The Sunday Age, The Canberra Times, Brisbane Times, WAtoday, Domain, Newcastle Herald, Essential Baby, Illawarra Mercury, Bendigo Advertiser, Queensland Country Life, Shoalhaven & Nowra News, Stock & Land, North Queensland Register, Narooma News, Bay Post / Moruya Examiner, Crookwell Gazette.

She has won a Walkley award in 2005 and a British Press Award in 1997.

“Can I get a soda?”

First words from the recipient of an historic world-first Australian-designed titanium artificial heart

By **Amanda Hooton** | *The Sydney Morning Herald*, July 15, 2024



The surgery team behind the US operation: Dr William “Billy” Cohn, Dr Alexis Shafii, Dr O. H. “Bud” Frazier, and Dr Daniel Timms, the Australian founder and chief technology officer of BiVacor.

“Can I get a soda?” These were the first words a 58-year-old man wrote on a clipboard after waking from his historic operation to implant a revolutionary, Australian-invented titanium heart. It was the first time the BiVacor total artificial heart has been placed in a living human.

The operation, more than a decade in the planning, happened on July 9 at the Texas Heart Institute in Houston.

The device’s inventor, 45-year-old Brisbane-born biomechanical engineer Daniel Timms, was present during the 4½-hour surgery in which the patient’s diseased heart was removed and replaced with the Australian device, a 650-gram titanium pump with a single moving part.

“It’s hard for me to get perspective on what we’ve achieved,” Timms told this masthead. “There are fleeting moments – in the middle of the night, sitting on a recliner beside the patient’s bed, trying to get some sleep – when

you suddenly think, yeah, it’s working. But mostly you’re just trying to dissect what’s happening and improve things for this patient, and the ones in future.”

The transplant surgeon who performed the operation, Dr Alexis Shafii, said the surgery “went great”. “Compared to doing it [during animal trials], it was actually much easier: the human anatomy is what it’s designed for.”

The medical team was amazed by the speed with which the patient,

suffering from end-stage heart failure, recovered. As Dr William Cohn, a transplant surgeon and chief medical officer of BiVacor, said: “When his breathing tube was removed, the first thing the patient said was, ‘I feel great.’”

In the following few days “he lost [8.6 kilograms] of excess fluid; off the breathing machine, able to walk. And not just a shuffling walk. An aggressive walk.”



Organ donation status became a federal issue even though conversations are local

Taking a person's organ donation status off their licence over 10 years ago (in all jurisdiction except South Australia was made to actually increase the number of donors nationally... how's that working out?

SA points the way as fewer Aussies give gift of life

By Lisa Wachsmuth – *The Advertiser*, 30 October, 2022

It's time to "reset the conversation" about organ donation as advocates call for a return to the system which allowed all Australians to register their decision to be an organ donor on their driver's licence.

South Australia – the only state where individuals can still register to be an organ donor on their licence – has the highest consent rate for organ donation in the country at 73 percent, far above the NSW rate of 51 percent.

Transplant Australia chief executive Chris Thomas said with rates of organ donation and transplants dropping in 2021 for the first time in a decade, there needed to be a "whole of community and health care response."

In 2021, 1174 Australians received an organ transplant, a decrease of 7 percent from 2020 and way down from 2019 when a record 1683 transplants were performed.

There was also a 9 percent decrease in the number of (deceased) organ donors in 2021, from 463 in 2020 to 421 in 2021. It corresponded with a drop in the consent rate nationally for

Sadly, there hasn't been much movement on this issue in all the other states (except SA) since Lisa Wachsmuth's article was written in late 2022, however Samantha Landy points out in her piece in the Herald Sun on March 4, 2024 that there is now a push for the other states to adopt South Australia's system.

Importantly, the general public just want a system that has the widest reach and best traction to support families to start having conversations about organ donation!

organ donation – in 2021, 56 percent of families approached about organ donation said "yes", compared with 58 percent in 2020.

"We have continually supported Australia's current "opt-in" system for donation recognising that donation is the greatest gift we can leave to others," Mr Thomas said.

"However we are concerned we are not presenting the public with simple and effective ways to support donation and we are encouraging all governments to reintroduce the opportunity to register as a donor on our driver's licence.

"It was a mistake to delete this option 10 years ago and we were privileged to

have our social cause embedded into this important life moment."

"What is clear from the statistics coming out of South Australia is that high registration rates can lead to high family consent rates.

"Therefore the greater number of people registered as donors has a direct effect on eventual donation rates."

Push to allow all Australians to register as organ donors via driver's licences

By Samantha Landy – *Herald Sun*, 4 March, 2022

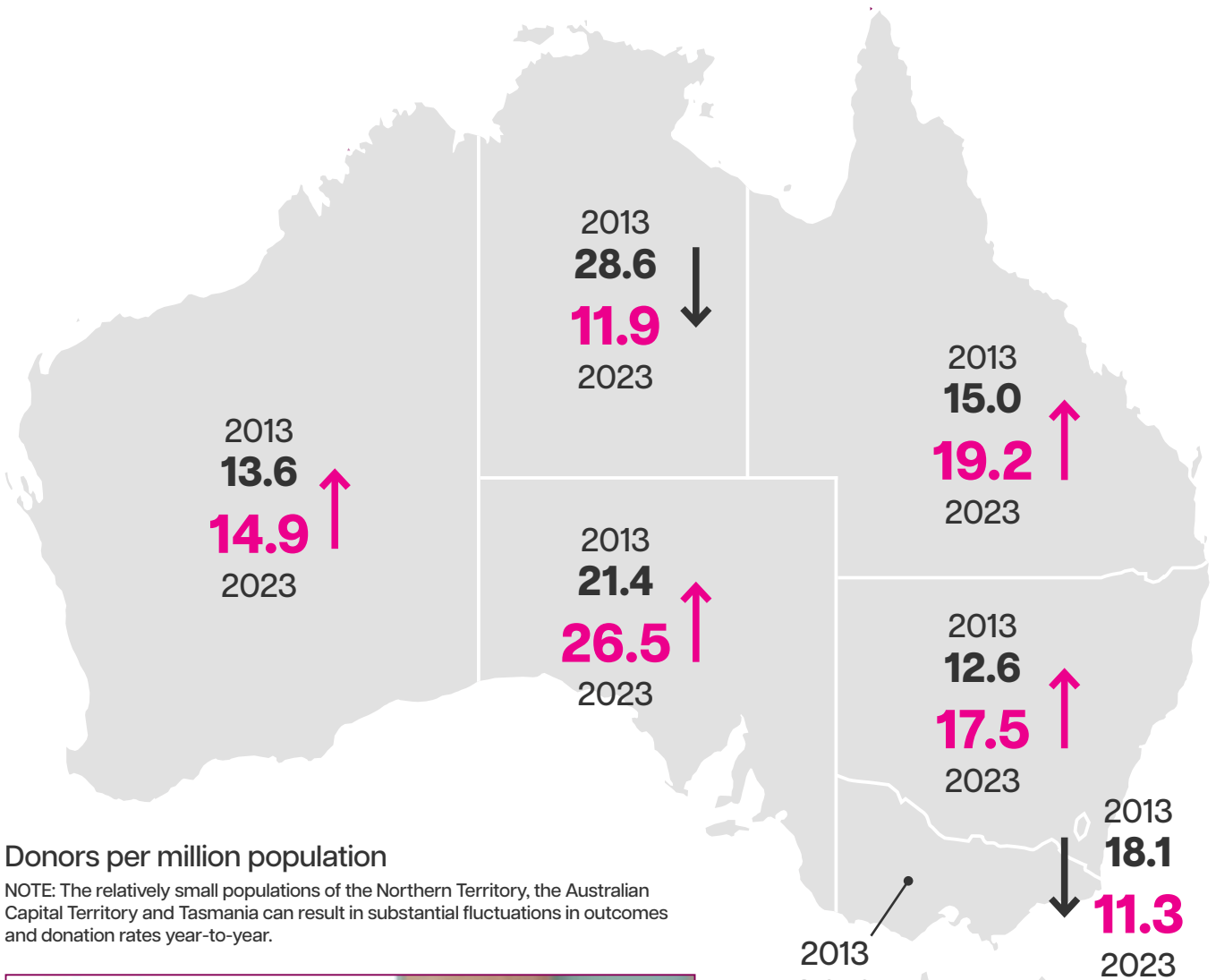
SA has a much higher proportion of registered organ donors than the rest of Australia, due to a system other states and territories are being urged to adopt to save lives.

The rest of the nation should follow South Australia's lead and allow residents to register as organ and tissue donors via their driver's licence, the state's health minister says.

While most Australian jurisdictions previously permitted residents to register when applying for or renewing their licence, only SA still does.

SA Health Minister Chris Picton said he championed the system in a meeting with his fellow state and territory health

Article continues on following page...



Donors per million population

NOTE: The relatively small populations of the Northern Territory, the Australian Capital Territory and Tasmania can result in substantial fluctuations in outcomes and donation rates year-to-year.



SHOW YOUR SUPPORT FOR ORGAN DONATION

STEP 1: Join the register by scanning the QR code and filling out a short form at donatelife.gov.au, or with three taps in your Medicare app

STEP 2: Let your family know you want to be an organ donor in the future



SCAN TO REGISTER
DONATELIFE.GOV.AU



STATE PERCENTAGE CHANGE PER MILLION POPULATION OVER THE LAST 10 YEARS

WA	9.55% increase
SA	23.8% increase
QLD	28.0% increase
NSW	38.8% increase
VIC	4.00% increase
TAS	109% increase
NT	60.0% decrease
ACT	37.5% decrease



A South Australia driver's organ donor status is clearly marked on their licence

ministers late last year, in what was “a welcome hearing”.

His recommendation was last week backed by a parliamentary committee investigating lagging donor rates in Western Australia, who agreed it had “proven successful” in SA and should be reinstated in WA.

“Digital driver’s licences (are) being explored in WA and other jurisdictions,” the report said. “This could provide an opportunity to introduce reform.”

Victoria is also undertaking a parliamentary inquiry aimed at increasing its registered donors – but last year, it heard VicRoads had not discussed restoring organ donation status on licences as part of an upcoming digital licence rollout.

SA has the highest proportion of eligible residents on the Australian Organ Donor Register (AODR), at 73 per cent. It is followed by Tasmania (48 per cent), NSW (41 per cent), WA (37 per cent), Queensland (31 per cent), ACT (27 per cent), Victoria (23 per cent) and NT (16 per cent), Donatelife figures show.

Further, 58 per cent of all 16 and 17 year olds on the AODR are from SA.

All Australians aged 16 and above can – and are encouraged to – register via donatelife.gov.au or the Medicare App. They should then tell their family, as their loved ones will decide whether they actually donate organs and tissue.

Mr Picton said SA’s strong donation rates were due to “a combination of factors, including excellent clinical work and commitment from intensive care staff in public hospitals”.

“But clearly, one of the components of the success has been the high registration rate, and that’s led by the (fact) people in SA have the ability, when they sign up for or renew their driver’s licence, to indicate that they intend to be an organ donor,” he said.

Mr Picton said Organ and Tissue Authority board member Oren Klemich – whose son Jack donated lifesaving organs to four people after he died suddenly at age 18 – had urged him to approach the other health ministers, and he was encouraged by their response.

“They will need to consider whether it’s practical for them to implement and speak with their transport ministries,” Mr Picton said. “But we’re very willing to share how it’s been a success here, how we put it in place and how it could apply in other states.

“Organ donations save so many lives across Australia.”

The WA parliamentary committee report also noted that the fact licence renewal occurred every five years could “give families more confidence

that their loved ones’ recorded decision (to support organ donation) is current”.

“Other opportunities for pathways to registration could include lodging tax returns, applying for a WA photo card, interacting with general practitioners and registering to vote,” it said.

Mr Klemich said he and his wife, Gill, knew of their son’s wishes to become a donor because he had ticked the box when applying for his first full licence.

“Jack was filling out the form and he asked Gill ‘what’s an organ donor?;’” he recalled. “She said, ‘if something horrible happened to you, the doctors in hospital can give your organs to people who need them’.

“He just ticked the box. Not many months later, we were asked, ‘he’s registered, but are you happy to donate his organs?’ We said yes.

“The driver’s licence registration system is incredibly simple and it will save lives.”

OTA chief executive Lucinda Barry added: “The evidence it clear that having the driver’s licence system leads to more people being on the register, and eight out of 10 families say ‘yes’ to donation if their loved one is registered.”

Six in 10 Australians want the ability to register via their driver’s licence, a YouGov poll revealed last year.

One organ donor can save up to seven lives and change many more through eye and tissue donation. But only 2 per cent of Australians die in hospital in a way where donation can be considered, and their families must then consent.

In 2023, 1396 Australians received transplants from 513 deceased donors.

donatelife.gov.au



Transplant Australia 'Thank You Rose'

The Transplant Australia 'Thank You Rose' is available through Treloar Nurseries when stocks are available.

This is a photo of Gaylynn Pinniger's rose. The rose spent many years in a pot and was looking good when planted in the front garden. Unfortunately, a very windy day meant the flowers had gone before Gaylynn got to take this photo. Since then she had some landscaping work done and the rose is back in a pot for the moment. She's doing everything she can to help it survive.

We would like to feature some photos and stories from other people about the rose in the next edition of *The Circulator*.

**Please send you photos and stories to our editor:
graeme.klemm@outlook.com**

The HLTTV provides a wide range of support

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

Our services and programs include:



Second Chance Accommodation Program (SCAP)

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



Donations to The Alfred

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



Fitness Grants

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



Emergency Financial Assistance

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



Heart to Heart Respite House (Barmah, Vic)

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



Information and support about transplants and organ donation

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



Peer Support

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



Social events for members of the heart and lung transplant community

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

Visit us at www.hlttv.org.au

Jose and Richard both celebrate over 30 years post transplant



Jose (left with Richard Metzke) are both celebrating over 30 years since their respective transplants

I received a new heart and lungs and my healthy heart was donated to another recipient - remarkable!

By Jose Lopez | *Heart and double lung transplant*

Life before Transplant was busy as I was married with two primary school aged sons and was a self employed plumber.

In about 1984 I started to show signs of illness and was diagnosed with a lung disease. My Lung Specialist, Dr. Mestitz, and other medical professionals suggested I retire (as they thought I didn't have long to live).

We decided to caravan around Australia as a family. At that time I was able to perform tasks as needed but with some help. I felt so blessed to be able to see our beautiful country and meet many wonderful and interesting people along the way. I had also travelled to my home country Spain to

see my family and friends and to visit the places of my youth.

Prior to 1990 I had become dependent on oxygen and needed a transplant. I was lucky that one became available through a wonderful donor and their family who gave me the life saving gift of a transplant.

I was transplanted with heart and lungs and my heart was a super heart that was transplanted into Keith Webb from Tasmania. We became friends after and visited each other's family a few times over the years. Unfortunately Keith passed away in 2004.

Post transplant I have seen my two sons grow into wonderful men with excellent careers. The eldest is married

and has three gorgeous children. They are the delight of my life. Also my wife Laraine and I have been able to travel extensively overseas and with some trips we have been accompanied by our second son and his partner.

In 1997 I took part in the World Transplant Games in Sydney. This encouraged me to take up Lawn Bowls and Ten Pin Bowling. I competed in other National Transplant Games and the World Transplant Games in Japan.

I have been interested in keeping in touch with the transplant family over the years and giving back where I can.

I am so grateful to my donor and their family for this life giving gift.

With our gift of life, we should enjoy what we have been given. With many thanks.

By Richard Metzke | Heart transplant

I had my first heart attack when I was 35. I was running a business. We had three children aged three, five and seven. Responsibilities were heavy.

A family friend came into help keep the business going while I recovered. My second heart attack happened two years later when I was 37.

I enjoyed sailing. My boat was a paper tiger 14 foot long Cat. When I had to give that up I sailed on a friend's yacht, a 24 foot space sailor. There where four of us and we sailed out of Royal Melbourne Yacht Squadron at St Kilda. It was a lot of fun.

A camper van was purchased and we went away camping during the Easter and Christmas breaks when the business was on holidays. If we had stayed in Melbourne I would be back at the business, no rest for the boss. One Christmas we drove up to Cairns with our van visiting friends. What a trip. We had a great time.

My health began to deteriorate and I had a few ventricular tachycardia attacks. One was when I was sailing up at Lake Nillahcootie. I had to be brought back to Melbourne by ambulance.

When camping up at Jarvis Bay I ended up in hospital. We got back to Melbourne and I had to go straight to Monash Hospital.

Another time I was on Port Phillip Bay sailing in a race. I had to be taken off the yacht at Mornington and transferred by ambulance to Monash Hospital again.

They fitted a better pacemaker to try to help. I ended up having to have an operation and they sent me to the Alfred hospital to cut out damage to

my left ventricle, do some more repair work and to do a couple of bypasses in 1989.

Still more dashes to hospital so it was decided to do a transplant in 1993. I was very lucky and once on the list I only waited three weeks and two days.

I received a heart from a male of similar age. If you say to me 'You have a new heart' – no I have a secondhand one and I have been given the gift of life.

Luckily for me my staff were very supportive but it is still very difficult trying to run the business as well as coping with your health and family.

The heart and lung support group was running before I was transplanted.

I was encouraged by The Alfred staff to join in the activities. This was being organised by a transplant recipient Avner and his friends.

These included a get-together at The Alfred and a Dinner Dance held in South Yarra. He was amazing and got everybody involved.

In 1994 a Committee was set up and the first issue of The Circulator was printed.

In 1995 the group formalised to become the Family Fund. I was asked to join the Committee. I am glad I did, becoming President for several years and several more years on the Committee.

My wife Prue also came along to Committee meetings. We have made friends with a lot of wonderful people. Prue and I have been involved with the Christmas and Easter BBQs at Fawkner Park. For a few years our son drove Santa to the park in his MG to the children's delight.

I eventually retired from the Committee as I thought a new President with new ideas is what is needed to keep any committee fresh and enthusiastic. This is why I recommend new people join. We still helped where we could.

Since retiring we have travelled around most of Australia in our van and camping where we could not take the van.

Going to Europe on many trips was wonderful. We went to all these amazing places, visiting our daughter and son while they were enjoying working in London and Zurich.

We moved to a Retirement Village 12 years ago. This has been a very good move for us.

I got back to playing golf (as a hacker) with wonderful friends. We have seen our children grow up and we have seven wonderful grandsons aged between 21 and 6.

I am very thankful to have been given another 30 years of life (so far) thanks to a donor family and the transplant team at The Alfred, some becoming friends.

With our gift of life, we should enjoy what we have been given.

With many THANKS.

FACT

All major religions support organ and tissue donation





Australia and New Zealand Heart Transplant Registry (ANZHTR)



Advancing Healthcare through registry data

By Kelly Marshall

Deputy General Manager

ANZDATA | ANZOD | ANZETD | ANZLKD

Clinical quality registries serve as structured systems using observational study methods to consistently gather clinical information for assessing specific outcomes related to a defined group of individuals with a particular disease, condition, or exposure. In simpler terms, they are organised databases that help track and evaluate health information for a specific group of people with a particular health issue, serving various important purposes¹.

In the Australian context, clinical quality registries are instrumental databases that focus on offering regular feedback to healthcare providers regarding their performance in specific aspects of care. The primary objective is to reduce variations in healthcare delivery and enhance overall patient outcomes. Recognised as essential for improving healthcare quality by the Australian Commission on Safety and Quality in Health Care, these registries are guided by a framework that provides recommendations and advice².

These organised databases, like the newly developed Australia and New Zealand Heart Transplant Registry (ANZHTR), play a crucial role in tracking and evaluating health information for individuals facing specific health issues.



Collaborating with the Australia and New Zealand Dialysis and Transplant (ANZDATA) registry group, cardiac experts have initiated the development of the ANZHTR. Led by a steering committee comprising clinical specialists from heart transplant units across Australia and New Zealand, with input from consumer representatives, this registry aims to become a robust platform for recording and reporting on all individuals who have undergone heart transplantation in the region.

Situated at the **South Australian Health and Medical Research Institute (SAHMRI)**, the ANZHTR benefits from its strategic location at the heart of the Adelaide BioMed City, the Southern Hemisphere's largest health and medical research precinct. SAHMRI's Registry Centre, a pivotal platform within the institute, facilitates collaboration among registries. It serves as a hub for maximising the value of registry data by integrating

it with other crucial data sources such as trials, surveys, biobank data, administrative datasets, and information systems through data linkage and research collaborations.

Core to the mission statement of ANZHTR is the improvement of patient care and outcomes for people with end-stage heart failure requiring transplantation. Consumer engagement and involvement is central to the work of most Clinical Quality Registries, and ANZHTR is no exception. By ensuring that a lived experience perspective is included in the work of ANZHTR, this core value of patient-centred research can be safeguarded.

As of 2024, the ANZHTR is transitioning from the development stage into an operational registry, anticipating data influx from all participating sites. The steering committee, supported by two consumers with lived experience of heart transplantation, is set to initiate the development of reporting tools. These publicly available tools will offer valuable insights to both the healthcare providers and the wider community, enhancing knowledge of heart transplantation and associated healthcare approaches. Ensuring the ongoing involvement and partnership with individuals who have firsthand experience, will ensure that patient safety is central to the aims and outcomes of the Australia and New Zealand Heart Transplant Registry.

¹ Glikich RE, Leavy MB, Dreyer NA, editors. Registries for evaluating patient outcomes: a user's guide. 4th ed. Rockville, MD: Agency for Healthcare Research and Quality, 2020. <https://effectivehealthcare.ahrq.gov/products/registries-guide-4th-edition/users-guide>

² Australian Commission on Safety and Quality in Health Care. Framework for Australian clinical quality registries. Sydney: ACSQHC, 2014. <https://www.safetyandquality.gov.au/sites/default/files/migrated/Framework-for-Australian-Clinical-Quality-Registries.pdf>

What is the SCAP?

The Second Chance Accommodation Program provided by the HLTTV

becoming a **MEMBER** of the HLTTV will assist us to continue to provide funding for this important program. See page 63 for the form.

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

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

In an attempt to meet demand, we increased our capacity under this scheme to three apartments in October 2013. With the great success of our fundraising efforts in 2014 we were able to meet current demand and increase the number of apartments to six.

In 2023 we forged a new accommodation partnership with local providers, **Rockmans Apartments**, in an arrangement that allows HLTTV

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

to continue to support the program after some very challenging pandemic years here in Victoria.

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

There is some financial assistance for those living more than 100km from Melbourne – each State Government pays an allocation per night to cover costs – but sadly doesn’t meet the entire cost. The HLTTV, through the SCAP, is able to contribute towards the shortfall, reducing the overall burden on families.

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

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

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



Celebrate the gift of life to the fullest

The 2024 Australian Transplant Games are being held in Canberra on 1–6 October 2024.

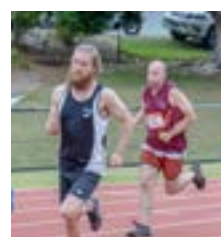
This is one of Australia's most inspirational sporting events, and it is coming to the nation's capital. Join the transplant community in the celebration of the gift of life, through sport.

The Games have two objectives: to promote organ donation and encourage more people around Australia to register and support donation; and to help recipients improve their health and fitness around their transplanted organ. Let's make the most of life!

Sports on offer at the Games include Athletics, Badminton, Basketball, Cycling, Darts, Pétanque, 5k Road Race, Sprint Triathlon, Swimming, Golf, Table Tennis, Tennis, Ten Pin Bowling, Volleyball, 7-a-side Football, Lawn Bowls, Suduko, Chess, Backgammon and Scrabble.

Please let us know if you participated at the Games. We would really like to update the HLTTV community about how people went and get some details about your experience.

Let us know via email to:
secretary@hlttv.org.au



Transplant Australia will be hosting the 17th Australian Transplant Games in Canberra, ACT, from Tuesday October 1 to Sunday October 6, 2024. The Australian Transplant Games is a team-based competition with Australian states and international teams competing.

All registrants must be members of Transplant Australia.

For further information about registration and participation in the Games

Email contactus@transplant.org.au

Call Within Australia 1800 827 757
Outside Australia +61 2 9922 5400

Post to PO Box 3444, Rhodes, NSW 2138





Although she found it hard to talk about the fact that someone had gifted life, she prayed to the day she died, in quiet for them in the privacy of her own heart and mind.

Remembering Carol Darroch

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

By Fiona Darroch | Carol's heart transplant was January, 1992

In her final days, surrounded by the breathtaking views of Melbourne's 'green belt' – Heidelberg, Eltham, towards the Dandenongs and Brisbane Ranges – Carol expressed her deepest wish to us, her five children.

She wanted us to offer prayers of gratitude to her heart donor and their family for the precious gift of 32 additional years of life—a gift she never thought she would have.

A Journey Begins

Carol's journey with heart troubles began in December 1969, just after the birth of her fourth child – myself.

The world was in the throes of a new era – the first successful heart transplant in South Africa in December 1967, and it captured headlines igniting hope for countless individuals like Carol. However, the early days of heart transplant medicine were fraught with challenges, particularly concerning post-transplant medications and immune system compromises.

After my birth, and struggling to recover from postpartum cardiomyopathy with no determinable cause, she spent weeks at Prince Henry's Hospital, grappling with the uncertainty of her condition.

With four young children to care for, she faced the first of many challenges with unwavering strength and determination.

A Life Filled with Love

Between my birth in 1969 and the arrival of our fifth sibling in December 1983, Carol's life overflowed with family friends and purpose. Our home was



a hub of activity, filled with music, storytelling, our Catholic community and large family.

Despite the challenges, Carol's spirit remained unyielding, buoyed by the unwavering support of our father, Harry, her community, her supportive sisters Helen and Maureen.

Facing Adversity with Faith

Over the next 15 years, and with no cure in sight, Carol's heart capacity slowly dwindled.

Despite this stoicism and unwavering faith, Carol welcomed the birth of our fifth sibling Caitlin in 1983.

Her Catholic Faith made her determined that she would have this child even at the cost of her life. These were critical and tense times for us all

and, even with a huge medical team, there was a real possibility Carol may not make it through the pregnancy, let alone the birth.

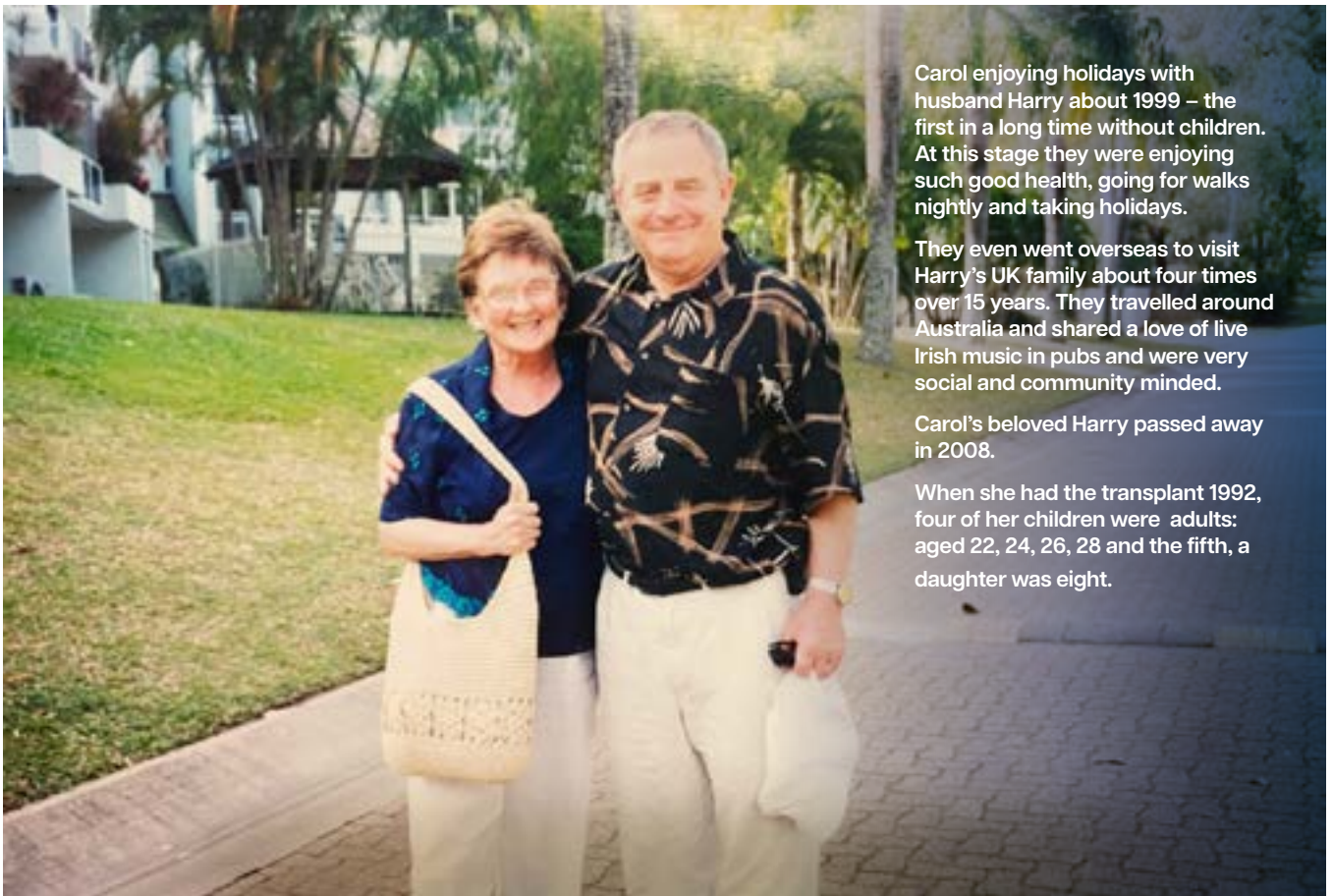
Miracles happened then and just months later, the headlines of Dr. Victor Chang's groundbreaking transplant on 14-year-old Fiona Cootes echoed the hope that sustained us through uncertain times. The medical work for transplants was continuing.

A Waiting Game

As Carol's heart condition worsened in the 1990s, with a now young child, the waiting game began—a tense period filled with false alarms and unmatched donors.

Yet, through it all, Carol remained steadfast, leaving behind practical instructions for us as a family and

Article continues on following page...



Carol enjoying holidays with husband Harry about 1999 – the first in a long time without children. At this stage they were enjoying such good health, going for walks nightly and taking holidays.

They even went overseas to visit Harry's UK family about four times over 15 years. They travelled around Australia and shared a love of live Irish music in pubs and were very social and community minded.

Carol's beloved Harry passed away in 2008.

When she had the transplant 1992, four of her children were adults: aged 22, 24, 26, 28 and the fifth, a daughter was eight.

facing the uncertainties with courage and grace.

A Second Chance at Life

In January 1992, after years of anticipation, Carol received the call that would change her life—a chance for a new heart.

The six-hour surgery was the longest wait of our lives, but Carol emerged stronger, embarking on a journey of healing and rediscovery.

Embracing Life's Joys

With her newfound lease on life, Carol embraced every moment with joy and gratitude. From joining an Israeli dancing class to pursuing her passions in volunteering and genealogy, she lived life to the fullest, inspiring us all with her resilience.

Although she found it hard to talk about the fact that someone had gifted life, she prayed to the day she died, in quiet for them in the privacy of her own heart and mind.

A Legacy of Gratitude

As we bid farewell to Carol in February this year, we carry with us her legacy of gratitude and hope.

My sister, a pharmacologist, has been a part of research, assisting in the search and remarkable find of a gene that likely holds the key to her own and my mother's heart failure: a gene called TTN. A new find that seems to unlock the cause of cardiomyopathy and leads the way to possibilities that are even more groundbreaking than a heart transplant. We will be watching this with hope.

A Future of Promise

As we navigate a world of medical advancements, Carol's journey seems to converge with the ongoing quest for innovation.

On the exact day of her departure on 20 February 2024, *The Age* newspaper ran front page headlines of Australia leading the race to build the world's first

long-term artificial heart to offer hope for future generations—a fitting tribute to Carol's enduring spirit.

In our hearts

On February 20, 2024, our beloved mother, Carol Darroch, peacefully left us, but not before she made sure her five children would have this said at her funeral:

"For Carol's heart donor and their family – we thank them for the gift of an additional 32 years of life.

For the staff of the Alfred and Austin Hospitals and the pharmacists and doctors who cared for Carol during her long life – we pray to the Lord.

And those she left behind – we too are so grateful for every single heartbeat she had since January 1992."

DonateLife Victoria Service of Remembrance

The 2023 gathering was a beautiful service. Please reach out to DonateLife if you would like to join the mailing list for the 2024 service this November.

Reflecting on last year...

**Saturday 18 November 2023
Collingwood Town Hall**

Words of welcome

Dr Rohit D'Costa, State Medical Director,
DonateLife Victoria

The purpose of the service is to acknowledge donors and their families who make life saving organ and tissue transplants possible.

It is an opportunity for those touched by donation and transplantation to meet others with similar experience.

Sharing stories of donation and transplantation

- **Abigail De Saram**, young daughter of donor, Nuwan
- **Ross Henkel**, heart recipient
- **Associate Professor Elaine Chong**, Head of Ophthalmology, Melbourne Health
- **Kelly Anderson**, daughter of donor, Kaye
- **Natasha Wagner**, mother of liver recipient, Evie

After a moment of silence and reflection messages were placed on the tribute trees.

It can be a very emotional day for many and the invitation to share afternoon tea and a chat following the Service was very welcome.

The beautiful music for the Service was performed by members of the Royal Melbourne Hospital Scrub Choir



- *Time After Time* – Cindy Lauper
- *Little Wonders* – Rob Thomas
- *I'll Stand by You* – Pretenders

Thankyou to the DonateLife team who once again organised the Service of Remembrance

The Service has been held in May for many years and some of our members were unaware that the Service is now held in November. If you would like to be on the mailing list you may like to contact DonateLife.



Take a moment to support the supporters

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

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



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

www.lungitude.com.au



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

www.hlppv.org.au

Taking a look back...



Carl Seales

Words by Gaylynn Pinniger

The “T” for Transplant Project was the brainchild of a heart recipient, the late Carl Seales (in conjunction with Mt Eliza Rotary Club). The aim of the project was to raise \$60,000 to purchase a second Novacor Artificial Heart Machine.

It started with the purchase of a T-Model Ford. Sponsors names were sign-written on the vehicle. With sponsorship of fuel and accommodation Carl headed off across Victoria speaking at Rotary, Lions and other clubs. The idea was to leave the T-Model on show at the local Ford Dealership during the week, advertising that Carl was in town. Cheques were sent back along the way.

Sue Tamblin was the Nurse Manager of the Heart Lung Transplant Service at the Alfred from 1992 until 2010. Sue was very much part of the original group that set up what is now known as the HLTTV when they sat down in the Basement Staff Café, no longer there.

President Carl Seales, Treasurer Jack Nolan and Secretary Alex Brunialti were some of those who were there in the early days. Jack was made a life member after many years of service.

As the 2002 AGM approached Carl, who was by then the most long-

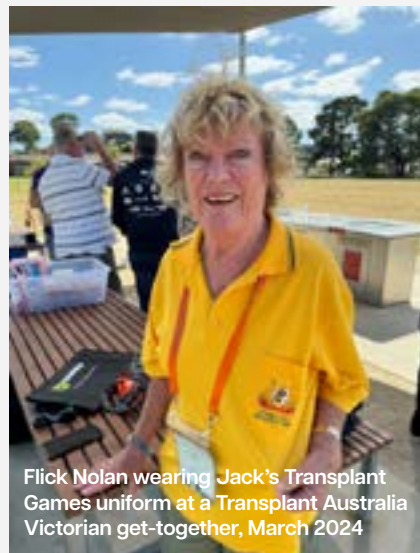
serving member and ex-office bearer suggested the idea of ‘new blood’ on the Committee. He and Richard Metzke did not re-nominate. This would be an opportunity to perhaps go in a new direction and come up with other ideas.

Since then many amazing volunteers have come forward to take on the Committee roles and have devoted much of their time. Various ideas have eventuated and fundraising has been a key part of this. Accommodation for pre and early post transplant patients needing to be in Melbourne from country Victoria or interstate was becoming a problem. When approached for assistance by an Alfred Social Worker, HLTTV agreed to help and the *Second Chance Accommodation Program* was established.

Committee meetings were historically held at the Alfred but these days are held online. Hopefully this allows more members to be involved. Computer skills are now important for volunteers. Times have changed since the beginning of the HLTTV.



Jack Nolan participated in the World Transplant Games Budapest 1999



Flick Nolan wearing Jack's Transplant Games uniform at a Transplant Australia Victorian get-together, March 2024

Carers have played a big role. Elizabeth Seales continued to be involved in the Committee after the passing of Carl and would travel from Phillip Island for the meetings.

Together with Jack, Flick Nolan attended meetings for many years at the Alfred and was involved in the Christmas BBQs. She stopped after Jack died in 2000 to concentrate on her own life. Flick is both a recipient wife (1993) and a donor wife (2000). Jack's two corneas and tissue were able to be donated. A mother was able to see her child for the first time.

Flick catches up with the transplant family at our BBQs. She is involved with a group called c-gals which means cultural girls and they organise lunches once a month. They donate to the Second Chance Accommodation Program as one of the group also has a connection. Her grandchild was the first girl to have a double lung and heart transplant when she was six. She died seven years later.

Recipients and their Carers have also been involved with Transplant Australia in the past and continue today. Jack Nolan participated in a number of Transplant Australia Games



All Essendon Football Supporters
Prof Don Esmore (right), Wayne Smith recipient of donor lung
in bed (Jack Nolan received donor heart)
Flick and daughter Emma in background



World Transplant Games Sydney 1997
(Jack Nolan second from left)

(originally known as Transplant Active) as well as World Transplant Games. Flick continues her involvement with Transplant Australia's Games.

Jack Nolan knew how lucky he was to have been healthy and able to enjoy life until he was older. He had played football at a high level. He felt for the children who had health problems at an early age. He thought something should be done and as Flick was a Physical Education Teacher they began a swimming program for those children

FACT

In 2023, 55% of families said yes to donation when asked in a hospital setting compared to 54% in 2022.

Since the national program first began in 2009, 18,144 people have received life-saving organ transplants from 6,417 deceased organ donors.



HLTTV Merch

Claude and Sam modelling a T-shirt with our logo at the recent Easter BBQ at Fawkner Park.

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

Victorian Recycling Scheme: Donate to HLTTV

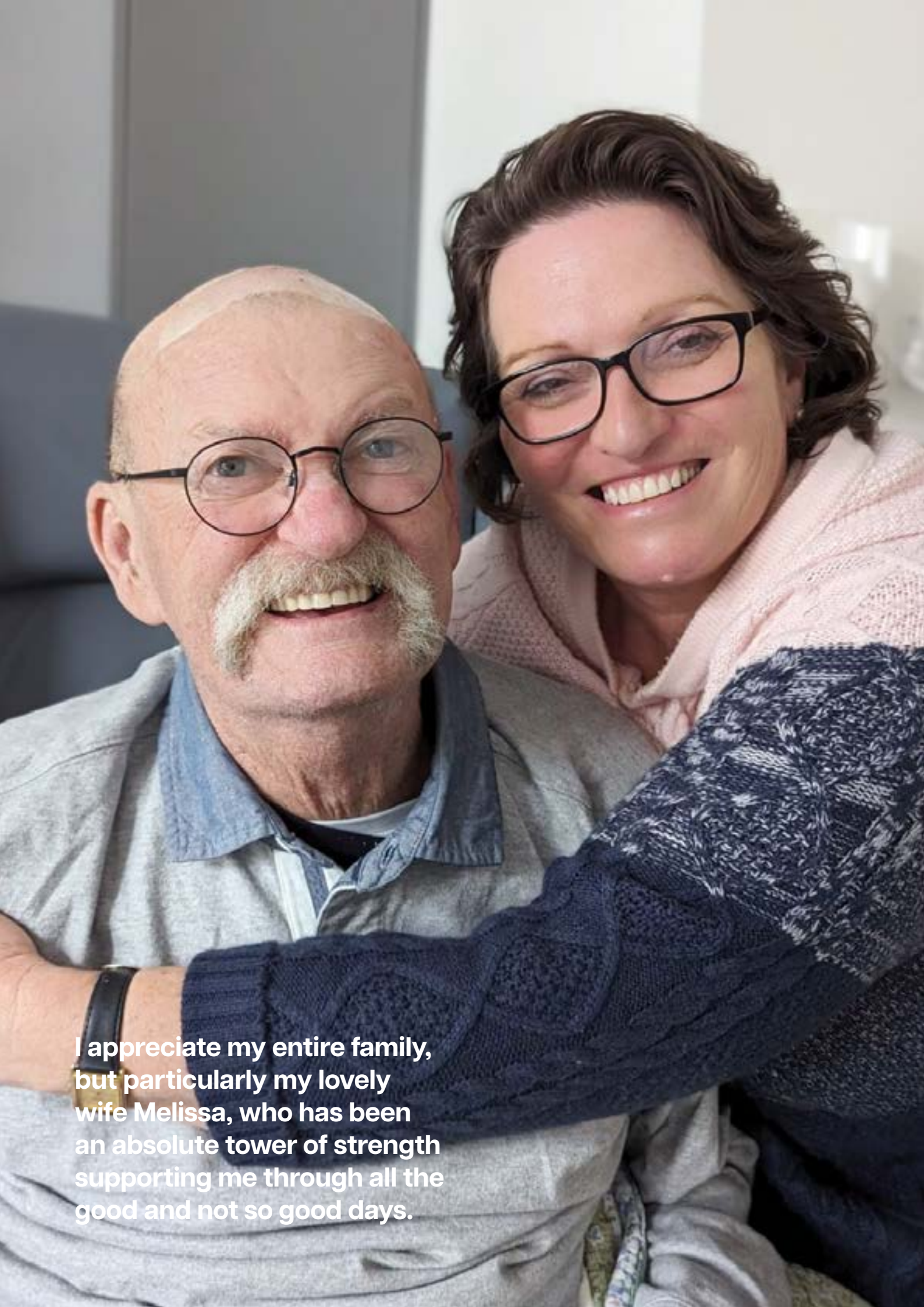
A great new initiative to help the planet by recycling and importantly make a donation to HLTTV.

Under the recently introduced recycling initiative in Victoria – the Container Deposit Scheme (CDS) - CDS Victoria will provide a 10-cent refund for every eligible drink container returned to recycling facilities from 1 November 2023.

Every bottle, can and carton you return helps to divert valuable containers from landfill. But don't forget not to crush your cans – keep them in their original shape.

If you choose, you are now able to donate your recycling refund to HLTTV.

HLTTV is a registered donation beneficiary with CDS. All you need to do is quote the HLTTV organization ID when you are at the recycling centre. The HLTTV ID No is C200 000 9731. Your refund will then automatically be forwarded by CDS to HLTTV's bank account. And you can request that a receipt be forwarded to you via email so that you can claim your donation as a tax deduction!



I appreciate my entire family, but particularly my lovely wife Melissa, who has been an absolute tower of strength supporting me through all the good and not so good days.

A promise made is a promise kept

I made a promise to my daughter, Jessica that I would walk her down the aisle and my transplant got me there.

By Norman Webster | Bi-lateral lung transplant on 15 December, 2014

My lung transplant journey began in November 2012 after I suffered a respiratory arrest. After spending almost seven weeks in our local hospital, the majority of this in ICU, I was later referred to Dr Jeremy Cailes, a respiratory physician in Geelong.

It was after several tests and consultations that Dr Cailes laid my options on the table. At this point I could choose to do nothing and have my health inevitably deteriorate, undergo a lung reduction, or a bi-lateral lung transplant.

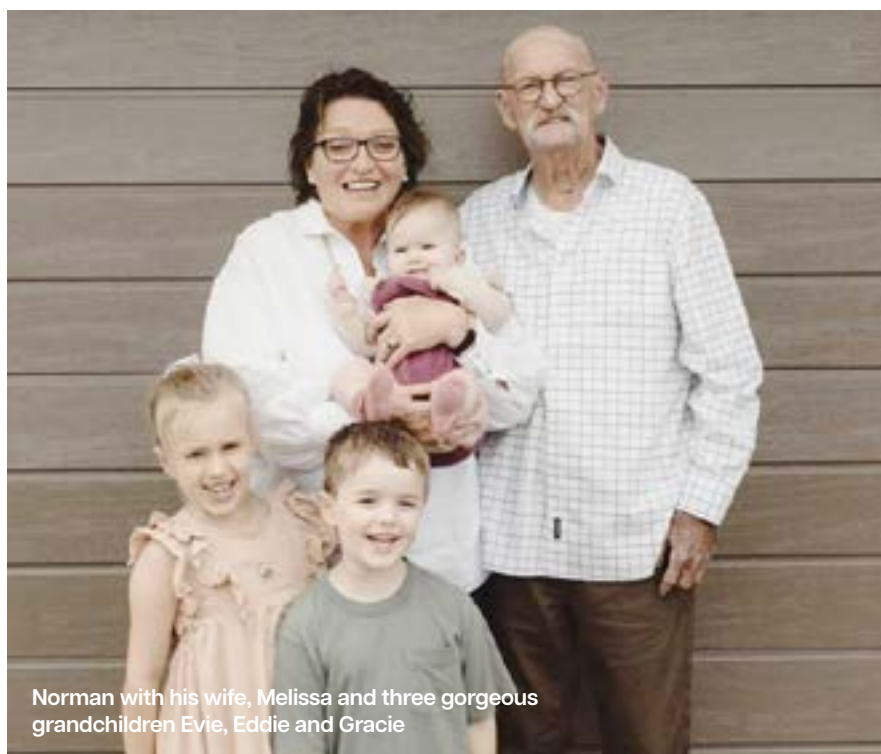
My wife, Melissa, and I were very emotional after this appointment as the word “*transplant*” had never entered our minds.

At this point I was an ex-smoker of several years and never imagined this to be an option for me. We had at this time decided not to share this information with anyone, not even our children, to allow us time to sift through what lay ahead.

We have three children Jessica, Matthew and Sophie and in 2012 the younger two were in the later years of secondary school and our eldest at University studying nursing.

I had a wonderful care team around me at home, which had ramped up after my respiratory arrest as it became increasingly evident that more was needed. My lung function was going down at each appointment even as I tried to maintain a certain level of fitness with my rehabilitation programs and umpiring cricket on the weekends.

It was becoming increasingly hard for me and Melissa to deny that nothing



Norman with his wife, Melissa and three gorgeous grandchildren Evie, Eddie and Gracie

was wrong and therefore we took Dr Cailes' advice to meet with the lung transplant team at The Alfred hospital.

Our first appointment at The Alfred was with Dr Miranda Paraskeva in early 2014 as I recall. Melissa and I were nervous but also felt this was our only chance to regain some normality to our family life. One thing that was clearly pointed out to us was that a transplant wasn't a cure but an opportunity to improve my health and would mean swapping one set of drugs for another to maintain ongoing health and prevent rejection of the transplanted organs.

I had to undergo numerous tests over the following months and although I was in obvious need of a transplant it still required me to be “*healthy*” enough overall to endure the surgery.

It was in about July of 2014 that our family was given the good news, delivered by Dr Trevor Williams, that I was eligible to go on the transplant waiting list.

Once we had been given this news, we needed to be ready to go at any time and the hospital required that they were aware of our movements if we travelled more than two hours from home in case we got “*the call*” to be in Melbourne at short notice.

We had been to visit our friends Mike and Heather in Bendigo in October that year and after this we never truly unpacked our bags in readiness.

Time began to tick by and our eldest child Jessica, who was engaged to Sam, continued to plan their wedding which was booked for January 10th

Article continues on following page...



Norman celebrating life with his wonderful and supportive family

2015. Melissa and I started to think that it might be a possibility that I wouldn't be able to attend the wedding if I wasn't called soon in order to allow the mandatory time in hospital post-transplant.

It was during this waiting period that we tried to go about our normal lives but always knowing that at any time we might have to leave home for this life-changing experience.

In the very early hours of 15 December, 2014 the much-anticipated call came. Melissa woke me and the rest of the family and within the hour we were on the road to Melbourne, to be at the hospital by 6.30am.

Melissa recalls driving with tears in her eyes until almost Colac as I phoned the family members who wanted to be contacted (no matter what time of the day it was). This was a great distraction for me to be talking to loved ones to help pass the time.

We had our children following behind as we made the trip to Melbourne and stopped at a roadside service station about an hour out from our destination so that the kids could wish me all the best with plenty of hugs and kisses in case things moved quickly when we got to the hospital.

Arriving at the hospital there were more blood tests and checks and within the next few hours I said my

goodbyes as I was transferred to the operating theatre.

I had made it through the surgery and while I was in ICU I realised the gravity of what had happened on this special day. Once I was able to go to the respiratory ward to continue my recovery I was up and walking, albeit a little slow, but I was extremely grateful and happy.

I had made a promise to walk Jessica down the aisle on her wedding day and I was able to keep that promise some four weeks later with a weekend pass to go home for the celebration.

It was a very emotional time for our family as I embraced this amazing chance for improved health that was given to me.

I am forever grateful to the donor who enabled me to begin a new life.

I appreciate my entire family, but particularly my lovely wife Melissa, who has been an absolute tower of strength supporting me through all the good and not so good days to follow.

We have met so many people during our journey who have received transplants and formed great friendships with them.

Melissa and I celebrated our 35th Wedding Anniversary this year and have also welcomed our three precious grandchildren Evie, Eddie and Gracie

to our ever-growing family during the years since my transplant.

I am one lucky bloke because not only have I survived my bi-lateral lung transplant almost 10 years ago, but I have also endured a triple heart by-pass procedure in 2021 and most recently a hip replacement after a mechanical fall in October 2023.

These have been very challenging times for me and my family and are constant reminders to me about my donor and their family who made a huge decision during the worst of situations and grief.

I have been fortunate to have so many doctors and health professionals like Dr Miranda Paraskeva, Prof Greg Snell, Dr Helen Whitford, Dr Trevor Williams, Prof Glen Westall and so many others.

We have always been surrounded by the generous nursing and allied health team which assists with my care. This care extends to numerous care providers at home that work in conjunction with the transplant team to maintain my optimum health.

I have so many things to be grateful for and will never forget my donor and family for the gift of life that was given to me.

Norman Webster

Giving back is cause for life!

Loula is a passionate volunteer

Words by Gaylynn Pinniger

The Heart to Heart Respite House Inc at Barmah is the Project of the Rotary Club of Nathalia. Loula Oliver is the current President and manages the running of the House. Past President John Attwood undertook this role with the help of his wife Eve for many years.

Loula moved to Nathalia in 1994 from SA when she got married. She met her husband Mark overseas. They were both on an Ashes tour. They love Cricket. Loula and Mark have three children - a son and two daughters. Their son is also in Rotary.

Loula was busy with her carer work in Aged Care, her family and finding time to drive seven hours to SA to visit her 92 year old mother when she was interviewed. Sadly since then she has lost her beloved mother.

Loula finds time for many volunteer roles. She is a volunteer with the Nathalia/Picola RSL. She has been on the Board of Mary of the Angels School for 13 years and is also co-President for the Australia Day Committee for Nathalia. She is an all round helper to many in the District.

Loula is a transplant recipient. She received a cornea transplant in September 1998. She had a two year old at the time and was running a dairy farm.



Loula Oliver and her beloved mother who has now sadly passed away



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



Exactly what the name suggests

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

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

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

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

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

There is plenty to see and do in the area: the paddle steamers and historic wharf at Echuca (as well as shops, hotels, cinema, etc.); a forest drive

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

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



into the Barmah forest is two-wheel drive friendly and there are plenty of bushwalking tracks (emus, kangaroos and even brumbies may be spotted);

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

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

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

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

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

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

Outdoors there is a carport, washing line, a verandah all around the house (with disability access ramp), an



outdoor table and chairs as well as an electric BBQ.

Guests are charged \$30 per night and there is also a linen hire charge of \$5 per stay (not per night), or people can, of course, bring their own. Of course the house is run as not for profit (thus the low rates), always has and will, and



we need to ask guests for payment because there are bills to pay.

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

Covid hurt us, as it did thousands of people and businesses; we also had floods in the area in October that



caused cancellations. This year only February and March had totals of 11 and 14 nights' stays respectively (bookings are usually for up to 6 nights but people stay anywhere between one and 10 nights).

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

Please support this very worthwhile respite house and help keep Bill Vickers' legacy alive.

Thank you.

Trudi Jones
trudi.jones76@gmail.com



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



GiveNow

**MAKE A
SECURE
DONATION**

Give more, give smarter, give better, GiveNow!
Donations to the Heart and Lung Transplant Trust (Victoria) are fully tax deductible and easy to do using the website below.

GiveNow.com.au



My time in Barmah, Moama and Echuca

You are welcomed by everyone you meet in this truly special part of the world, any time you choose

A stroll down to the Murray River, the Barmah wet lands, or just calling into the Barmah Hotel. The meals are delicious, renowned for their Parma's and the Friday night Meat Raffles.

Hot afternoons and balmy nights, you can enjoy a BBQ on the front verandah, the night sky's are filled with an amazing galaxy of stars.

A time to relax and explore the Murray River's historic charm of Barmah, Moama and Echuca.

Visit The Moama Day Spa, where you can use the facilities at the tranquil rock pools.

Relax on the lounges around the pool, bring your own refreshments and snacks. The pool is open to the public Monday to Friday for a cost of \$15.00 including beach towels.



For a great day out with children go to the Adventure Playground on Perricotta Road, near the Sports Club.

Pack a picnic or BBQ facilities are available.

If you enjoy a wander around a market, the Moama Market is on every second Sunday. The Moama Market is filled with Crafts, Food, Plants, Music, Clothing and more. Check out the dates and make a plan to get there.

The Echuca Farmers Market is on the first and third Saturday of each month, for fresh local produce.

The Port of Echuca will take you back in time with a trip along the Murray River on one of the Paddle Steamers, or the horse drawn carriages.

The Port's Gallery and Information Centre is open every day.

Echuca and Moama is Australia's Paddle Steamer Capital. Steeped in heritage, the twin towns are the home to the world's largest fleet of operating Riverboats, as well as fine dining restaurants and an array of water sports.

Explore the wine region, with fine Wineries, Morrisons Riverview, St Anne's and a selection of Breweries and local Distilleries. Before you leave the Murray, pop in to the Great



Bookings for Heart to Heart House, Barmah are easily made by contacting Martina McArdle (martina@hlttv.org.au)



Aussie Beer Shed and Heritage Farm Museum. This popular Museum is one of the most unique tourist attractions in Australia. They have an incredible array of iconic Aussie paraphernalia, including 20,000 beer cans from Australia and around the world, classic cars, a partially restored WW1 canon, Coca Cola collection and more.

Visit the Echuca Chocolate Factory for a sweet treat. Situated in the Old Echuca Port precinct just a short distance to the Heart of Echuca. You can enjoy delicious hand-made chocolates, sweets, hampers and chocolate liqueurs.

The Beechworth Bakery is set along the Campaspe River. Leave some room for their famous vanilla slice.

The Moama Beach with picnic and BBQ areas, lush green grassland and surrounded by nature lets you relax under the red gum forests and cool off in the Murray River.

If you visit in July, entertainment will be filled with The Winter Blues Festival, Moama Lights, Winter Lights Trail and much more.

If you are staying at the 'Heart to Heart House' it's a great experience and you are sure to make wonderful memories.

Martina McArdle
Double lung transplant
11 September 2009

Barmah and beyond, in the spring

We had decided on a short break and were wondering where to go. After reading the Spring edition of The Circulator we decided it was again time to visit Barmah and enjoy the Heart to Heart Respite House.

We left Melbourne on a cold wet morning and arrived in Barmah to a beautiful blue sky after visiting Nathalia.

The house felt so welcoming on arrival and later we found out that it was Loula Oliver who had been there getting it ready for us. The notice board out the front shows how many people and businesses contributed to giving us this wonderful Respite House. It makes you appreciate the House even more.

You can relax and enjoy the serenity of Barmah or you might like to do what we did. We went on an adventure and travelled up through Deniliquin



for morning tea, through Conargo to Jerilderie for lunch and back via the Tocumwal Aviation Museum in time for dinner at the Barmah Pub. Another day we drove the longer distance to Albury to have lunch with a friend, stopping for coffee at Rutherglen, one of our favourite towns.

On the way back we called in to see a cousin in Mulwala. We were constantly criss-crossing the Victoria/NSW border and the GPS took us on roads we had never been on before. This time we took a drive into the Barmah National Park which we hadn't done before.

Perhaps on our next visit we should just relax and do some walking – not just to the Pub!

Gaylynn Pinniger
Heart Transplant 2002



**ACTIVEWEAR
THAT GIVES BACK
BUY TX ACTIVE APPAREL
AND KICKSTART AN ACTIVE
LIFE FOR A TRANSPLANT
RECIPIENT TODAY!**

**TX
ACTIVE**



GIVE THE GIFT OF AN ACTIVE LIFE!

TX Active Slouchy Jumper

Will become your

'go to' comfy jumper for all seasons. \$75

TX Active Compression legging

Italian recycled fabric. Dual pockets, quality long lasting tights. \$60



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

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



Track pant \$69

Track top \$19

TX Active Unisex Tracksuit

Suitable for exercise, lounge or streetwear.

Our classic fit, track & field suit
is a nod to retro street fashion.

TXACTIVE.COM.AU

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

Details: 4-way stretch polyester spandex.

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

TO FIND OUT MORE AND JOIN OUR CAMPAIGN...

WWW.TXACTIVE.COM.AU

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



Celebrating together

Our social events are a great way for our transplant family to celebrate life and feel supported.

Christmas BBQ 2023... Misty but nice!

Unfortunately it was very cloudy and raining on and off in the early morning of Sunday 26 November, 2023. Luckily there was only some mist now and again as we ate and held the raffle draw. Not an umbrella in sight. If the BBQ had started at 3 o'clock we would have had the perfect day with Fawkner Park looking stunning. A small group were able to stay on to enjoy it.

We missed our long time BBQ friends. The good news is that we met some very new transplant patients and their families. We appreciated the effort they made to come along as most were soon to be returning to their country towns. We hoped they would be able to make the journey to join us at another BBQ. We wished them well.

Thanks to Martina and her family for the huge effort they once again put in to organise the Christmas BBQ. Thanks also to all the helpers on the day.

Despite the weather it was a great day with a visit from Santa who had treats for everyone.

Make sure you are on the mailing list just in case there are any last

minute changes. You can email membershipofficer@hlttv.org.au or ring Wanda on 0435 743 146 to make sure you are on the list.

Easter BBQ 2024

As those of you who attended will know, the HLTTV Easter BBQ at Fawkner Park on 17 March was a great success.

The weather was kind to us, and those in attendance enjoyed catching up with family and friends. The BBQ meal was up to it's normal high standards – thanks to our chefs on the day.

The children in attendance enjoyed an Easter egg hunt, and the Easter Bunny attended to ensure everyone at the BBQ received an Easter egg and a bunny hug!



Always remember these dates...

- Easter BBQ (a fortnight before Easter Sunday)
- Christmas BBQ (last Sunday in November)



Tips on travel post transplant

You will know the moment that it feels right for you, but there are some important things to remember

It is advisable for solid organ recipients to wait at least a year before embarking on overseas travel. Bone marrow recipients need to wait a minimum of 2 years before travelling.

Plan and consult your transplant doctor well in advance to be reviewed and assessed for risks associated with travelling. You will be at the highest risk of infections during periods of greater immunosuppression. This is usually during the first year following transplantation or during intense treatment for rejection.

Travel can be unsafe for recipients especially if you are travelling to places where infectious diseases are common, sanitation is poor and quality medical care is limited. Updated travel advisories can be obtained from the Department of Health or Centers for Disease Control and Prevention.

Take enough medication in your hand luggage and in your checked-in baggage. If your luggage is lost, you have enough in your hand luggage, and if your hand luggage is stolen, you have enough in your checked-in luggage.



Keeping all medications in their original packs can help if you're questioned by customs/baggage inspectors as you go through airport security.

Request a letter from your doctor specifying all medication you take, including the dosage and frequency. Carry this letter on you as you go through baggage screening.

Liquid medicines are subject to the same volume restrictions as any other liquids (100 ml per container). Carry a doctor's letter if you need more than the allowable limit of medicines on-board.

While travelling overseas with PBS medicines **use a medicine declaration form to declare the medicines** you are carrying.

Consult your doctor for flexibility with taking medicines. Prepare a schedule to adapt to changes in time zones.

Always take a greater supply of medicines than you need in case your trip is extended, you experience delays or miss flights. You can do this by renewing scripts in the minimum allowable time – some prescriptions include the date when the script can be next be ordered (approximately 21 days). When travelling overseas, talk to your doctor about stocking up. Your doctor can communicate with the pharmacist for extra supplies

Print a list of your medications, doses and include the names and contacts of your transplant doctor, transplant unit and other emergency details. Try to keep this list in a pocket or wallet at all times when travelling.

In many countries, foods containing raw or under-cooked meats and fish, such as sushi in Japan, can be risky for recipients. **Stay away from shellfish like oysters, uncooked prawns and crabs as they can contain harmful bacteria.**

IMPORTANT DATE TO REMEMBER

Membership renewal 2024–2025

HLTTV membership fees are due on 1 July 2023 for the 2023–2024 financial year. There are several payment options: cheque, Paypal or EFTPOS and you can renew online. Details available on the HLTTV website:

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

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

IMPORTANT DATE TO REMEMBER

HLTTV Xmas BBQ & Walk

Sunday 24 Nov 2024 | 11.30am to 2.30pm

HLTTV 2024 Xmas BBQ & Walk will be held in Fawkner Park, adjacent to The Alfred again this year to celebrate and connect heart and lung transplant recipients.

The BBQ is a great social event for pre and post transplant patients, families, carers and friends. BBQ and drinks are provided (including vegetarian options).

Great raffle prizes offered on the day – donations can be left at 5th Floor Reception at The Alfred. **Contact Martina on 0409 957 492 or email martina@hlttv.org.au**

Circulator word search 2 & 3

Can you find all the words listed below?

R	U	L	E	L	G	N	I	H	T	A	E	R	B
L	E	A	M	E	G	S	I	N	O	B	B	A	A
U	A	N	P	O	X	Y	G	E	N	N	U	A	H
N	R	E	H	I	I	N	H	A	L	E	R	B	E
G	E	Y	Y	G	Y	R	I	B	A	R	R	R	R
S	Z	I	S	N	A	S	R	M	O	R	H	O	Y
N	I	Y	E	A	T	A	U	H	M	B	E	N	R
I	L	P	M	S	N	N	G	R	P	M	N	C	A
I	U	H	A	S	A	N	N	Y	X	Y	R	H	N
O	B	S	P	I	R	O	M	E	T	R	Y	I	O
E	E	H	E	R	U	C	Y	N	T	A	C	T	M
Z	N	Y	P	R	U	B	L	E	A	P	A	I	L
C	N	N	A	O	R	A	C	O	U	G	H	S	U
I	M	A	E	C	Y	U	M	M	U	C	U	S	P

Word search 2

BREATHING
BRONCHITIS
COUGH
EMPHYSEMA
INHALER
LUNGS
MUCUS
NEBULIZER
OXYGEN
PULONARY REHAB
SPIROMETRY

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

Word search 3

CONTROL
DIABETES
EMOTIONAL
EXERCISE
MANAGE
MENTAL
NUTRITION
REDUCE
SIGNS
SLEEP
SMART
STOP
VISIT
WALKING
WATCH

DID YOU KNOW?

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

For more information visit www.servicesaustralia.gov.au

Circulator word search 2 solution
from page 65

R	U	L	E	L	G	N	I	H	T	A	E	R	B
L	E	A	M	E	G	S	I	N	O	B	B	A	A
U	A	N	P	O	X	Y	G	E	N	N	U	A	H
N	R	E	H	I	I	N	H	A	L	E	R	B	E
G	E	Y	Y	G	Y	R	I	B	A	R	R	R	R
S	Z	I	S	N	A	S	R	M	O	R	H	O	Y
N	I	Y	E	A	T	A	U	H	M	B	E	N	R
I	L	P	M	S	N	N	G	R	P	M	N	C	A
I	U	H	A	S	A	N	N	Y	X	Y	R	H	N
O	B	S	P	I	R	O	M	E	T	R	Y	I	O
E	E	H	E	R	U	C	Y	N	T	A	C	T	M
Z	N	Y	P	R	U	B	L	E	A	P	A	I	L
C	N	N	A	O	R	A	C	O	U	G	H	S	U
I	M	A	E	C	Y	U	M	M	U	C	U	S	P

Circulator word search 3 solution
from page 65

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



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

Notice of Annual General Meeting 2024

Tuesday 19 November at 7.30pm

Venue/Zoom will be confirmed with RSVP

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

The business of the annual general meeting shall be:

1. Confirmation of Minutes of the 2023 AGM
2. Presentation of the 2024 Annual Report
3. Presentation of the 2024 Annual Financial Report*
4. Elect officers of HLTTV and the ordinary members of the committee; and
5. Confirm appointment of the auditor for 2023-2024
6. Any special business (if any)

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

The 2024 agenda and minutes of the 2023 AGM are available on our website in the Events, AGM section.

Any member intending to bring any other business before a meeting must notify the Secretary in writing, or by email to secretary@hlttv.org.au NO LATER than 12 November 2024.

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

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

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

If you plan to attend the AGM, please RSVP by Friday 8 November, 2023.

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

www.hlttv.org.au



Your membership counts



Heart and Lung Transplant Trust (Victoria) Inc

PERSONAL DETAILS

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

NEW MEMBER

I wish to become a member of the Trust

EXISTING MEMBER

I wish to renew my membership

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).

Lung(s)	Month	Year
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 \$20 applies to all other categories of membership.

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

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

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

Please return this form to:

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

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



Members may also join online and pay membership and donations via direct debit bank transfer.

Please visit <http://www.hlttv.org.au> and follow the 'Membership' links.

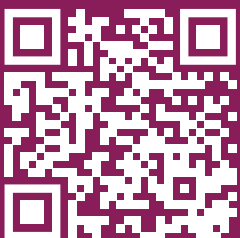


DonateLife

BE THE REASON SOMEONE ELSE GETS A SECOND CHANCE AT LIFE

REGISTER AS AN ORGAN
AND TISSUE DONOR TODAY
AT [DONATELIFE.GOV.AU](https://donatelife.gov.au)

SCAN TO REGISTER



JAYLYN RECEIVED A HEART TRANSPLANT

