# the Circulator

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

Spring Edition | 2020 | Issue No. 101

‘THE BRIDGE OF DREAMS’

A CLOSE LOOK AT THE EXCEPTIONAL VENTRICULAR ASSIST PROGRAM AT THE ALFRED

ISSUES LIKE SKIN CANCER AND OSTEOPOROSIS ARE VERY IMPORTANT CONSIDERATIONS IN POST-TRANSPANT LIFESTYLES

IMAGINE DEALING WITH CANCER, HEART FAILURE AND LIVING WITH BI-VADS FOR THREE YEARS. A MOTHER TELLS A POIGNANT STORY ABOUT CARING FOR HER INSPIRING SON DURING HIS CHALLENGING JOURNEY

IN IT FOR THE LONG HAUL

IN THIS ISSUE, LET’S CELEBRATE THE EXTRAORDINARY LONG-TERM OUTCOMES OF EIGHT OF OUR LONGEST SURVIVING RECIPIENTS

# President's message

**With metro Melbourne's daily COVID-19 numbers heading in the right direction, sunshine increasing and flowers blooming, it's finally starting to feel like there's light at the end of a very long tunnel.**

It's wonderful to feel some hope after some very long, hard months here in Melbourne, and this edition of the *Circulator* features many stories of hope, determination and resilience from those on the transplant journey. Thanks yet again to our incredible editor, Graeme. I found myself particularly moved by the love, faith and hope shared by Michelle Richter in *'A mother's love'.* Just beautiful.

I also want to send a very special 'thank-you' to HLTTV committee members Adam, David, Graeme, Maarit, Martina, Petra and Sam. Like you, committee members have been living with lockdown challenges. Missing out on milestone birthday celebrations, being separated from family for meaningful celebrations and negotiating difficult health and personal situations.

Despite this, each of them has continued with a generosity of spirit and focus that has been inspiring to me, especially when I've felt quite overwhelmed with health challenges within my own family. While I'll always see transplant as the greatest gift, I truly believe the way transplant recipients and their families 'give back' is something to be equally celebrated. So thank you to our committee members, and thanks to each of you who 'give back' through connecting, sharing and supporting each other.

## Locked down, not shut down

While your HLTTV committee members miss hosting our usual social events, we've still been super busy supporting those on the transplant journey and exploring grants and other opportunities. Most recently it's been my privilege to advocate for members experiencing tenancy/renting issues, to coordinate financial assistance and to provide many hours of telephone peer support.

## Can you lend a hand?

I'm mindful that there's so much more that can be done to support our fellow carers and those at all stages of their transplant journey. With our **AGM coming up on Tuesday 11 November,** it would be wonderful to have a few more 'hands on deck'.

We'd love to have a few more ordinary committee members, particularly if you're interested in providing peer support.

All positions become available at the AGM, so if you fancy yourself as President, or even better, Vice-President – get in touch with our brilliant Secretary, Maarit (secretary@hlttv.org.au).

2021 is going to be a big year!

## Stay the course and stay safe

Of course, there's still a lot of wariness for those of us who are at-risk or caring for someone at-risk due to compromised immune status.

The good news is, we can continue to follow the public health essentials to keep ourselves safe:

- Wear a fitted face mask when you leave your home
- Practice good hygiene and regularly/thoroughly wash your hands
- Maintain physical distancing by keeping at least 1.5 meters away from others
- If you feel unwell, get tested

Here in Victoria, the best way to stay informed is to visit the DHHS website dedicated to coronavirus (COVID-19) at **www.dhhs.vic.gov.au/coronovirus**

Stay safe and well,

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

# The link between grieving and grateful

**The National DonateLife Family Support Service provides comprehensive support for families who say 'yes' to organ and tissue donation. Meet Michelle – a key staff member.**

In Victoria, the healthcare team in the hospital and the DonateLife Donation Specialist Nursing Coordinators assist the family with their immediate practical, physical and emotional needs. All potential donor families are offered support at the time of end-of-life care whether or not the donation proceeds. When the family leave the hospital, my role comes into play.

As the Donor Family Support Coordinator, I contact and provide support to all Victorian donor families. As a consequence, I am in the privileged position of hearing peoples' stories and learning a great deal about what donation means for those involved.

Every families' experience of death and donation is unique and dependent on their relationship with the person who has died, their family situation, their world view and their personal histories. We have learned through conversations with donor families, and through research, that the majority of family members find comfort in knowing their loved one has helped others.

During my conversations, many donor families will ask about the well being of those that have been helped. For some people, donation and transplantation help with the search for meaning that can be part of the process assisting a family member to come to terms with their loss. On numerous occasions, I have heard a mother, father, partner, grandparent or sibling say "we're so glad he/she was able to do this; it is the only positive out of an awful situation".

After speaking to donor families for around ten years, I have also learned that the majority are open to receiving a letter from their love one's recipients. A letter or card from the person who has benefitted from their decision helps to confirm that they have made the right decision and that there is a real person whose life is improved. I imagine that for some recipients the prospect of writing to the donor family is overwhelming and challenging. Writing to their donor family without including identifying information may also be an obstacle for some recipients. It is worth keeping in mind that you can say a lot about yourself without the information being identifying. There is also the option of keeping your letter brief, just letting the family know that you are sorry for their loss and that you appreciate their donation.

DonateLife have produced a brochure to assist recipients who choose to write and this can be found at **donatelife.gov.au**

**Michelle Skinner**
Donor Family Support Coordinator
DonateLife Victoria

# Secretary's message

**How are you all going? I'm sitting here today with fingers crossed that now we are seeing numbers heading south, lockdown restrictions may be eased and we can safely move around and see family and friends again.**

I've had one visit to the Alfred and was able to spread a bit of love and thanks to the Transplant team and other support services, as I celebrated my 10-year anniversary this year.

We, as a family, were able to enjoy a lovely celebratory lunch together, in between lockdowns. I feel so much love for my donor and their family, who through their incredibly sad time, agreed to donate to me and others the gift of life.

There are quite a few members celebrating major anniversaries and big birthdays this year. (I've got one of them too!) No big parties, unfortunately, so Zoom cocktails and a delicious meal at home will have to do, for now.

With restrictions in mind, we will probably need to hold our Annual General Meeting via Zoom, or a combination of both, as we have done for the last two Committee meetings. All members are encouraged to join our meetings. Just RSVP to me, secretary@hlttv.org.au and I will forward details for the venue and/or meeting codes.

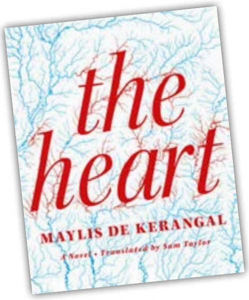
My family out celebrating with me.
From left: Nick, Elena, me, Zac and James

We have had a relatively quiet time as a Committee, however we are still involved in the on-line Post-Transplant Education Sessions, getting the website up-to-date (there are some glitches we are aware of), preparing our Annual Reports and submitting applications for some government grants. Hopefully, we will able to provide some safe social activities in the near future.

I hope Spring brings you some warmth with the sunshine (must find the sunscreen and hat again) and you and yours stay well.

If you have any queries please don't hesitate to contact me.

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



## Feel like a good read?

### The Heart

**by Maulis de Kerangal**

*Just before dawn on a Sunday morning, three teenage boys go surfing. While driving home exhausted, the boys are involved in a fatal car accident on a deserted road. Two of the boys are wearing seat belts; one goes through the windshield. The doctors declare him brain-dead shortly after arriving at the hospital, but his heart is still beating.*

*The Heart takes place over the twenty-four hours surrounding the resulting heart transplant, as life is taken from a young man and given to a woman close to death. In gorgeous, ruminative prose, it examines the deepest feelings of everyone involved as they navigate decisions of life and death.*

*As stylistically audacious as it is emotionally explosive, The Heart mesmerized readers in France, where it has been hailed as the breakthrough work of a new literary star. With the precision of a surgeon and the language of a poet, de Kerangal has made a major contribution to both medicine and literature with an epic tale of grief, hope, and survival.*

https://www.goodreads.com/book/show/25664510-the-heart

## Tales from isolation

Hello. I'm currently sitting on my computer wasting more time, but what else is there to do? The excitement is building for a trip to the shops tomorrow, it will be the tenth time I have been out since the 18th March. All but one of those outings was to hospital. I had lesions on both hands removed. All good though, I can now eat with a knife and fork again.

A few weeks ago I reached the 10-year anniversary of my double-lung transplant. It was a very quiet celebration but I am so grateful for this milestone. It took me about four months after the transplant until I could walk again but oh, the feeling of breathing again on my own after being on oxygen for about 20 months!

Since my transplant I have another two grandsons who I might never have known. I've joined a few groups including day trips and lunches as well as knitting (all on hold of course). I'm starting to really miss Bingo and Pokies – only went once a week. I suppose 'Free Pokies' on my computer is some consolation.

Because I was so unwell before, my clothes shopping went out the window, but I'm glad to say I have made up for lost time.

I am very fortunate to have a wonderful and caring family, wish we could see each other more – but we will.

**Kathryn Wright**

***Ed Note:*** *Over the years Kathryn has been busy knitting bed socks for charity including raising funds for HLTTV as a way of giving back.*

# The bridge

## *The Alfred's Ventricular Assist Device program commenced in 1990 and provides a 'bridge-to-transplant' for an increasing number of patients.*

**Heart Failure is prevalent in today's society affecting 2% of the adult population in Australia, with an estimated 500,000 people with heart failure.**

The heart's function can be impaired due to a variety of diseases that affect the heart's ability to pump blood around the body effectively. Diseases that may cause heart failure include: ischaemic disease (heart attacks), viral illnesses, drug therapy used to treat cancer and congenital diseases. Sometimes heart failure occurs without a known cause and is referred to as idiopathic heart disease.

When the heart cannot pump blood as well as it should, fluid starts to accumulate in the lungs, abdomen, legs and ankles. Less blood is pumped forward to all the important organs including brain, kidneys and muscle. This accounts for the typical symptoms of breathlessness, tiredness, muscle fatigue and fluid retention. A person with a weak heart feels tired and short of breath after very simple activities, such as walking or climbing stairs.

For some, the heart can severely decline in function and no longer be able to cope despite standard medical management, including oral medications and devices such as a pacemaker. The next step required is assessment for heart transplantation, or in very sick people, a mechanical heart pump called a Ventricular Assist Device (VAD).

**WRITTEN BY:**

**Janelle McLean – *MCS Co-ordinator* (left) and Dr. Peter Bergin – *Cardiologist, Medical Head of Heart Failure Cardiology and Heart Transplantation***

The *Alfred Hospital's Ventricular Assist Device program* commenced in 1990, only one year after Professor Don Esmore began the Heart Transplant programme. The first generation of pumps implanted were 'pulsatile flow' devices, that were very large (the size of a washing machine) compared to the miniature 'continuous flow' devices that we utilise today. Most patients who need a VAD require a pump for the left side of the heart only – LVAD. Rarely, some patients require two pumps, one for the left and one for the right, called a BiVAD.

Since the early days there has been a steady increase in growth of VAD numbers implanted each year, as the newer generation devices have become more reliable and safer.

In the last few years we have implanted devices into 20-30 patients annually *(see Table 1 below).*

In the last 12 months, The Alfred have been supporting between 28-32 VAD patients at any one time *(see Table 3 opposite).*

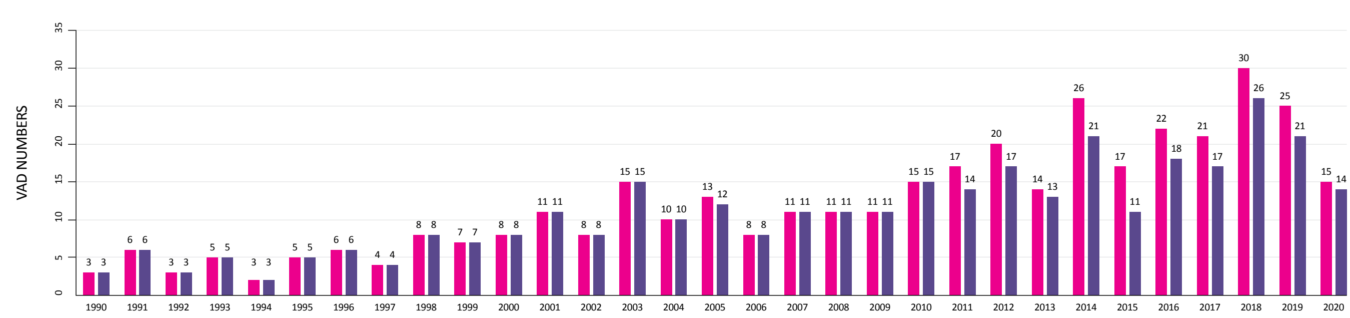
## The Alfred VAD Team

The Alfred VAD team consists of members from multiple disciplines. We all work together to achieve best patient outcomes for our VAD patients.

Team members include:

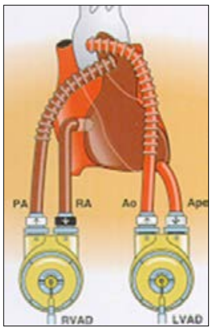
- Heart Failure Cardiologists, Fellows and Registrars
- Cardiothoracic Surgeons
- Mechanical Circulatory Support (MCS) Co-ordinators
- Perfusionists
- Intensive Care Medical and Nursing
- Cardiac Nursing staff
- Physiotherapists
- Pharmacists
- Dietitians
- Psychologist
- Social Worker
- Occupational Therapist
- Palliative Care

**Table 1 – devices implanted since 1990**

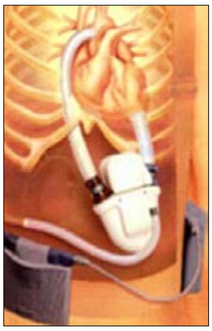


# of dreams

## The Evolution of Mechanical Circulatory Support (MCS) devices

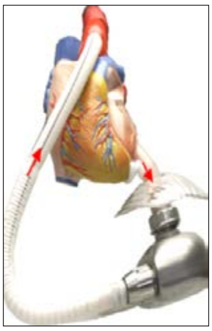


**Thoratec PVAD**
- Paracorporeal
- Pneumatic
- Pulsatile
- Uni or Bi-ventricular
- Large
- Multiple moving parts

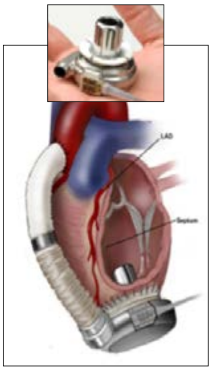


**Novacor LVAD**
- Implantable
- Electric
- Pulsatile
- Large
- Multiple moving parts

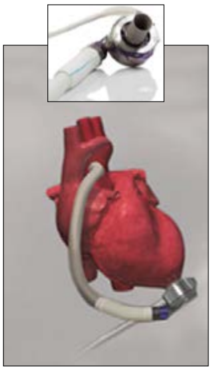
**HeartMate II LVAD**
- Implantable
- Axial
- Electro-magnetic
- Continuous flow
- Small, 281gm
- Rotor spins on ruby bearings
- Pump pocket



**Ventrassist LVAD**
- Implantable
- Centrifugal
- Electro-magnetic
- Continuous flow
- Small
- Single moving part – rotor
- Pump pocket



**HeartWare LVAD**
- Implantable
- Centrifugal
- Electro-magnetic
- Continuous flow
- Smaller, 160gm
- Single moving part – impeller
- Pericardial space



**HeartMate 3 LVAD**
- Implantable
- Centrifugal
- Full magnetic levitation
- Continuous flow
- Smaller, 200gm
- Artificial Pulse
- Pericardial space

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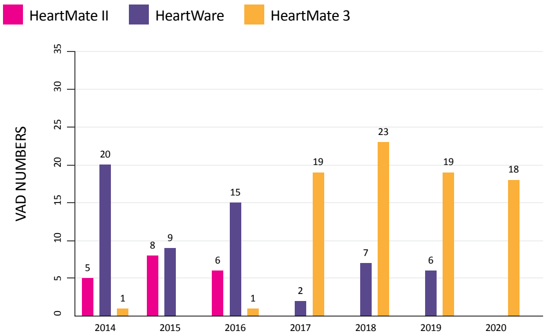
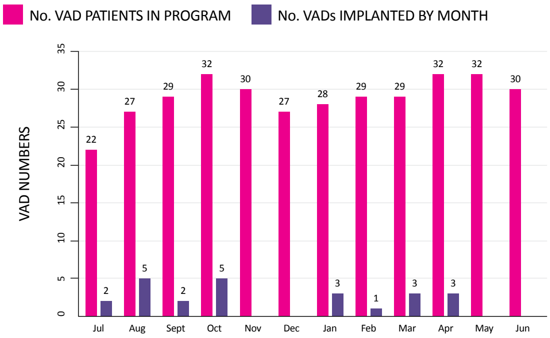
### Table 2 – (LVAD and BiVAD) by type trends



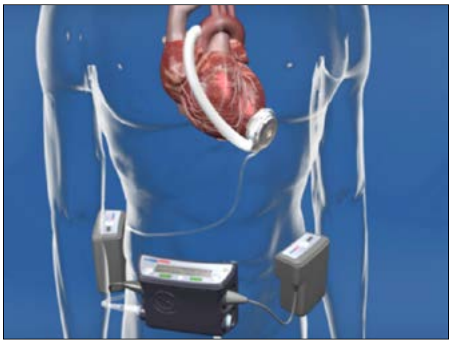
### Table 3 – VADs supported – financial year 2019-20



### The MCS Co-ordinators

The *MCS Co-ordinator* role is diverse and varied. Of all those in the MCS team, we are the first port of call for our VAD patients. Some might call us "jack of all trades". Three of us share the role to *educate* and *case-manage* the VAD patients and their caregivers.

## Current VAD devices used at The Alfred



**HeartWare HVAD**
- 160mg (about the weight of an iPhone)
- Continuous flow, no pulse
- Single moving part – impeller

**HeartMate 3 LVAD**
- 200mg
- Continuous flow – artificial pulse
- Full magnetic levitation

## Impact on patients using the technology

From the cumbersome, washing machine sized Thoratec PVAD (1990) first generation implanted pump which required patients to remain in their hospital bed prior to their transplant limiting their transitional recovery.

To the relatively tiny, 200gm latest generation HeartMate 3 LVAD which allows the patient full lifestyle flexibility to rehabilitate and regain a degree of fitness and normality prior to their transplant.

# The bridge of dreams

(Continued from page 5)

As well as providing education to many stakeholders *(see right)*. Education is a key component of the role.

## Education

MCS education consists of learning about:

- The LVAD pump, device components and function
- Battery and AC power management
- Alarms and management
- Recognising signs of infection, bleeding and stroke
- Anticoagulation management
- Doing the driveline dressing
- Performing activities of daily living while on the VAD

Other key MCS Co-ordinator responsibilities:

- Driveline dressing education
- Running the VAD outpatient clinic
- Booking and reviewing tests of VAD patients
- Managing VAD equipment
- Maintaining and developing databases and guidelines

## Case Management

Case management of the VAD inpatients and outpatients requires attention to a variety of elements.

The aim is to keep patients living at home in the community, to reduce complications, to improve patient/caregiver quality of life and to increase patient empowerment. *(The graphic at the top of the opposite page depicts these factors.)*

The patient and primary caregiver are taught all about the VAD. We aim for all our patients to be independent with their VAD self-management. So most patients do not require a full-time caregiver.

It is recommended that there is a support person for the first three months post implant hospital discharge, until the patient has rehabilitated enough to be managing on their own.

Regularly attending the VAD gym to exercise under physiotherapy guidance is key to helping patients get back to their best physical ability. Attending the VAD gym and meeting other VAD patients has been reported to be the most valuable aspects to VAD patients supporting each other. This enables them to be able to share experiences, frustrations and solutions to similar situations they are facing. This is also the same for caregivers.

## Education Model

**Patient / Caregiver** →

- Inpatient education
- Re-education 6 monthly

**Internal**
(Alfred Health) →

- Nursing staff (Ward, ICU, ED)
- Medical staff (Ward, ICU, ED)
- Cardiology
- Perfusion and Theatre staff
- Physiotherapy
- Allied Health
- Rehabilitation facility
- Other departments (Dialysis)

**External**
Interstate (TAS / SA)
Regional / Rural
Metropolitan →

- Nursing staff
- Medical staff
- Physiotherapy
- GP
- Paramedics
- Biomedical Engineering

A suite of HeartMate 3 equipment and materials used to education patients / caregivers using that device

Covid-19 has limited the ability for these face-to-face interactions over the last 6 months. However, now that the second wave in Victoria is easing, we have recommenced the VAD gym which should see patients reconnect.

Not only have the VAD pumps improved significantly but also the care and outcomes have changed dramatically.

Originally patients would stay in hospital for months and months until they were transplanted. Now patients are typically discharged home after 3-4 weeks, have a very active gym program and in many instances return to work and driving.

A key component of improving the patient's quality of life has been the ability to return patients home to regional Victoria or interstate, South Australia is a great example of this.

Primarily, we are the implanting adult centre for the state of Victoria, South Australia and Tasmania.

We have robust relationships with our shared care centres in South Australia – the wonderful dedicated teams at Flinders Medical Centre and Royal Adelaide Hospital.

Over the last 10 years we have also had share care centres with our Tasmanian partners in the Royal Hobart Hospital, Launceston General Hospital and North West Regional Hospital.

We receive referral of patients from these centres for Heart Transplantation or VAD implantation. We successfully work to return these patients safely to their local communities, primarily managed by the respective local teams.

## Case Management Here are the key components that are assessed and evaluated at each clinic visit

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HeartMate 3 Pump


HeartMate 3 Controller and Power Unit


New personal device to check INR range as a prevention for blood clotting in the pump

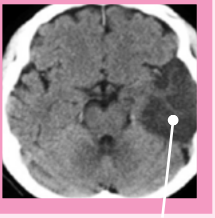
### VAD Management and Compliance

- EQUIPMENT
- DRIVELINE
- BLOOD PRESSURE
- ANTICOAGULATION
- FLUID
- MEDICAL ADHERANCE
- EDUCATION


Preventing a thrombus developing in the pump is a key element of 'anticoagulation'


Driveline entry needs constant monitoring


Using a Dopler to measure blood flow


Preventing a stroke (bleed or blood clot in the brain) is a vital part of 'anticoagulation' and 'blood pressure monitoring'.

## Distance to our patients – Victoria

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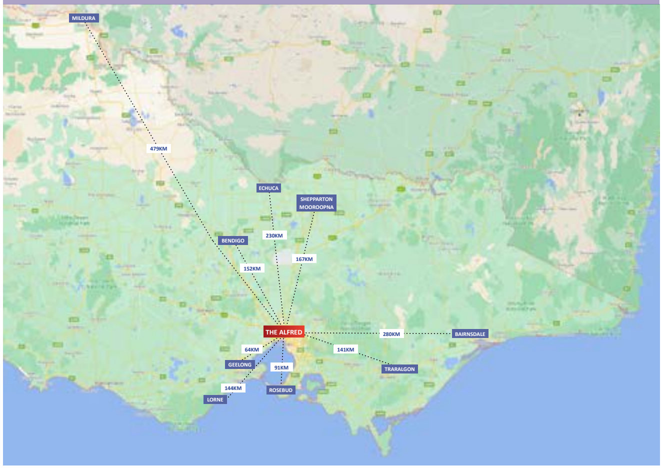

## Distance to our patients – Interstate

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The Alfred Hospital VAD and Transplant Shared Care Centres

*"I personally know nine of the Alfred faces below, and so many more, from my own **ECMO** to **VAD** to **rehabilitation** to **work-up** to **waiting** to **transplant** to **recovery** to **normal life** experience. It's a long journey that is thrust upon a growing number of people due to heart failure. Although it was the most challenging experience I have ever faced, it has been the most interesting and enlightening time of my life, learning about myself, my family, my friends and **the sheer tenacity of the incredible professionals who took over my life** and shepherded me from induced coma and life-support to a successful transplant 19 months later. **In simple terms, the Alfred VAD program is like a time machine... it buys time while you wait for a heart.** I look back on a photo of my old heart attached to the VAD after my transplant and wonder how I ever got there! **I don't think I'm alone when I think of, and thank, these extraordinary people every day for their service."*** Graeme Klemm, Editor

### Some of the Alfred's dedicated VAD Program staff

Back row - L to R: **Tanieka Lake** - MCS Co-ordinator, **Peter Bergin** - Cardiologist, **Andrew Taylor** - Cardiologist, **James Hare** - Cardiologist, **Su Ling Tee** - Heart Failure Fellow, **Angie Leet** - Cardiologist

Seated - L to R: **Janelle McLean** - MCS Co-ordinator, **Julia Rix** - MCS Co-ordinator, **Ashlee Linton** - Heart Failure Co-ordinator

as well as **Dr David Kaye** - Head of Cardiology *(inset left)* and **Hitesh Patel** - Cardiologist *(inset right)* who were unable to be present for the photo.

# Transplanting the Alfred

*The Alfred Hospital has a patient catchment including South Australia, Tasmania, metropolitan and regional Victoria and southern NSW.*

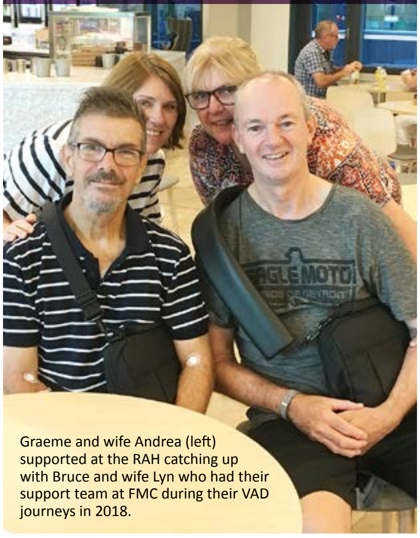
**A key area in which the Alfred assists their catchment is training clinical professionals in Advanced Heart Failure – encompassing the Ventricular Assist Device (VAD) program along with heart and lung transplantation.**

South Australia, with a total population of 1.7 million people, has a significant burden of heart failure. In addition, South Australia supports the specialised cardiac management of patients who reside in the Northern Territory.

Whilst South Australia does not have a local state-wide transplant implant centre that performs implantation of left ventricular assist devices (LVADs), two of the major hospitals in Adelaide have strong professional links to The Alfred Hospital.

The recognition of patients with advanced heart failure and prompt referral to a Heart Transplant Centre is essential to provide the opportunity for eligible patients to have the opportunity to access the life-saving therapies of ventricular assist devices and cardiac transplantation.

One of the key aspects of the journey on a VAD is the support of other patients and carers who are going through a similar experience.



Graeme and wife Andrea (left) supported at the RAH catching up with Bruce and wife Lyn who had their support team at FMC during their VAD journeys in 2018.

**WRITTEN BY:**

**Dr Michael Stokes**
Cardiologist
Royal Adelaide Hospital

**Dr James Gunton**
Cardiologist
Flinder Medical Centre

Royal Adelaide Hospital

A key objective presently in the management of these patients, who receive an LVAD, is the earlier transfer of cardiac patients post-LVAD and transplantation back to South Australia for ongoing treatment and rehabilitation.

Both the Royal Adelaide Hospital and Flinders Medical Centre have strong medical links to The Alfred Advanced Heart Failure Unit via **Dr Michael Stokes** at the Royal Adelaide Hospital (RAH), along with **Dr Rob Minson, Dr James Gunton** and **Dr Christine Burdeniuk** at Flinders Medical Centre (FMC), all of whom have completed Fellowships in Advanced Heart Failure at The Alfred Hospital.

Additionally, **Assoc Prof Carmine De Pasquale** at FMC and **Dr Enzo DeAngelis** at RAH both undertook Clinical Fellowships in Heart Failure at St Vincent's Hospital, Sydney, the other major heart and lung transplant hospital in Australia.

Flinders Medical Centre

In addition, specialised cardiac nursing expertise through **Tim Pearson** and **Lee-Anne Horsfall** is present at both hospitals in supporting South Australian patients who receive a VAD.

There is also a solid network of support through the Exercise Physiology and Psychology Services provided by **Dianne Littlechild, Karen Linehan, Chris Hart** and **Duncan Lodge.**

The Alfred Advanced Heart Failure Unit takes great pride in training medical and nursing staff in the management of LVAD patients.

A significant number of nursing staff from South Australia have spent short training periods on site at The Alfred to provide training in the care of LVAD patients. This enables many patients to live home in Adelaide with professional expertise and support to enable successful physical rehabilitation and a planned smooth journey towards cardiac transplantation.

The South Australian Hospitals and the South Australian LVAD recipients are extremely grateful for this solid professional link to The Alfred Hospital that provides access to this therapy.

**15 patients from South Australia have been implanted at The Alfred in the last 5 years with 11 returning home to SA supported on a VAD.**

# A truly inspiring pioneer

## *He inspired a generation of young cardiothoracic surgeons and many healthcare professionals with his drive and ability.*

**Internationally renowned, and highly respected, Professor Don Esmore was Director of the CJ Officer Brown Cardiothoracic Unit at the Alfred Hospital when he passed on 12 February 2013.**

His was a life of incredible achievement and deserved honours. He was a professor at Monash University, an officer of the *Order of Australia,* and a recipient of the *Prime Minister's Centennial Medal.*

He is remembered for his peerless surgical skill, clinical acumen and quite extraordinary instincts.

On completing high school he went straight into medical school at the University of Melbourne and graduated as a bachelor of medicine and surgery (MBBS) in 1973.

He worked as an intern, resident and registrar at various hospitals, including Preston and Northcote Community Hospital, Prince of Wales, Wollongong and Sydney.

The path to a professional life in cardiothoracic surgery began when he moved to Sydney's St Vincent's Hospital as a cardiothoracic surgical registrar, gaining his fellowship of the Royal Australasian College of Surgeons in cardiothoracics in 1983, then a fellowship of the Royal College of Surgeons of Edinburgh in cardiothoracics in 1984.

An 18-month fellowship at Papworth Hospital in Cambridgeshire followed, and he also travelled through North America to gain further experience, returning to St Vincent's Hospital as a staff cardiothoracic surgeon.

He was pivotal in the renaissance of cardiac transplantation led by Victor Chang, and was a key team member in the first heart-lung transplant performed at St Vincent's Hospital during that period.

**Words by Trevor Williams and Peter Bergin (senior clinicians at The Alfred Hospital) memorialising the passing of colleague Don Esmore AO in an article in the Sydney Morning Herald, February 22, 2013**

Professor Donald Esmore AO MBBS 1973

In 1988, The Alfred hospital in Melbourne was chosen to run the second national cardiothoracic transplant program, and in early 1989, with great support from the Alfred's administration and clinical staff, Don got straight down to business. After only a few weeks, Don performed the first heart transplant in this new era of transplantation at the Alfred.

**Remarkably, he performed 30 consecutive heart transplants without an early death – an epic feat.**

A year later, in March 1990, he performed the program's first heart-lung transplant, utilising the recipient's heart in a second recipient - the first ''domino'' heart-lung transplant in Australia.

Many innovations followed, including single-lung transplantation in 1990; double-lung transplantation in 1992; and long-term support and retrieval using then-evolving technology allowing advanced life support where mechanical ventilation failed - so-called extracorporeal membrane oxygenation.

By 1996, the Alfred team was performing the most lung transplants per head of population in the world. Don's passion to use every heart and lung donor, even those that others perhaps regarded as marginal, was pivotal in this achievement. Donor retrievals from Perth, Darwin and New Zealand often pushed the ischaemic time (the period without blood supply) to the limits of conventional wisdom and often beyond, especially where it was recognised the planned recipient had only a very short time left to live. Despite often extending well beyond the then accepted criteria, he achieved superb outcomes.

His team was encouraged to innovate. Early on in the Alfred program, Don recognised the need to increase donor heart utilisation, just as he later did for lungs. He performed heterotopic heart transplants (piggyback hearts) to allow smaller hearts, previously discarded for lack of a suitable recipient, to be used in selected patients.

His surgical team assessed many modified lung techniques, including anastomotic (joining) techniques for lung transplantation, and approaches to cut down lungs to fit smaller recipients, particularly children. In 2011, the Alfred was awarded Nationally Funded Centre status for paediatric lung transplantation.

One of Don's great professional loves was artificial heart technology. He recognised that donor numbers would never be enough to service the growing needs of end-stage heart-failure patients. Not only did he embrace existing artificial heart technology, but his great expertise in ventricular assist device support led him to a pivotal role in the development of an implantable left ventricular assist device (LVAD) called the VentrAssist.

**He personally performed more than 10,000 open-heart surgeries.**

He has inspired a generation of young cardiothoracic surgeons and many healthcare professionals with his drive and ability. His clinical acumen was extraordinary. He made observations and decisions well ahead of others who would only understand the astuteness of his plans and therapy well after the patient was in recovery.

# IN IT FOR THE long haul

31

YEARS

### John (Jack) Jones

**Lives:** Wantirna (VIC)
**Transplanted:** December 1989 H
**Surgeon:** Professor Don Esmore/Dr Andrew Cochrane

**Thoughts:** My transplant has given me many more years with my wife and two daughters. It has allowed me to see my five grandchildren grow up and develop into fine adults. I now have five great grandchildren with another one due in October. It also meant I could return to work for ten years until I retired. It has allowed my wife and I the time to travel overseas to Scotland and America and around Australia with a caravan. My wife and I celebrated our 63rd wedding anniversary this year. And it allowed me to take up golf and win my club's senior tournament.

30

YEARS

### Jose Lopez

**Lives:** North Geelong (VIC)
**Transplanted:** April 1990 HLL
**Surgeon:** Prof. Don Esmore, Trevor Williams, Greg Snell

**Thoughts:** I was the second 'Domino double lungs and heart' transplant (my super heart was transplanted to Keith Webb from Tasmania). The new life I was gifted enabled me to see my two boys grow from primary school aged children to graduating university into the professional people they are now. I have been able to travel to visit my family many times in my country of birth – Spain and many other countries as well as through this beautiful country Australia. I am most grateful for seeing my eldest son marry and have three beautiful grandchildren.

30

YEARS

### Edward O'Bryan

**Lives:** Port Fairy (VIC)
**Transplanted:** March 1990 H
**Surgeon:** Professor Don Esmore

**Thoughts:** At the time of transplant, my wife Sue and I had two girls aged six and four, and a third girl born two years after my transplant. My past thirty years has been spent with Sue giving each of our three children a good education, taking them to every part of Australia and also overseas to broaden their education before university. Two are now qualified Lawyers and one a Clinical Psychologist. These years have given me the greatest joys of my life, stemming from the generosity of one kind heart donor and the outstanding medical team at The Alfred Hospital.

28

YEARS

### Kylie Chappell

**Lives:** Glenroy (VIC)
**Transplanted:** January 1992 H
**Surgeon:** Dr Tom Karl

**Thoughts:** I was only a young teen when I had my transplant. If the transplant had not gone ahead, I wouldn't have made it to my 14th birthday in April and all the other little milestones such as 16th, 18th and 21st birthdays. I got to pass my VCE and attend my Year 12 Formal like a (semi) normal teen. I was able to marry (still married), work – firstly part-time in retail, then full-time as a Lab Tech at Melbourne University. And enjoy life, love and friendship as much as I can – a beacon of hope to all I meet.

**Let's celebrate the incredible long-term anniversaries of these proud transplant recipients in 2020. Transplantation gives recipients a second chance at life and when that extends to decades, recipients and their loved ones have a great deal to celebrate. Outstanding!**

28

YEARS

### Carol Darroch

**Lives:** Viewbank (VIC)
**Transplanted:** January 1992 H
**Surgeon:** Professor Don Esmore

**Thoughts:** Since my transplant I have done many things including volunteering at my youngest child's school and a hospital. I am blessed with five children and seven grandchildren. My late husband and I travelled in Australia and the U.K., Ireland and Europe where we visited his family and I followed the footsteps of my ancestors. I am very interested in genealogy and have published a book about my great, great-grandfather. Thank you to all involved in my transplant at the Alfred and those since who have helped me.

28

YEARS

### Richard Rowlands

**Lives:** Albury (NSW)
**Transplanted:** June 1992 H
**Surgeon:** Professor Don Esmore

**Thoughts:** Obviously the first 12 months were the hardest, but to honour my 'second chance' I ended up volunteering for Meals on Wheels and then Villa Maria Society (nursing homes for the aged) for 5 years. I attended a transplant meeting one night at The Alfred and found myself helping to start the *Alfred Concierge Service* (now the *Volunteers*) with my wife (Pat) for 18 years – the best time of our lives. We had spent a bit of time in Albury in our travels and decided to retire there. We've also enjoyed some lovely trips and cruises to make the most of our time together.

28

YEARS

### Libero Viola

**Lives:** Wonga Park (VIC)
**Transplanted:** October 1992 H
**Surgeon:** Dr Gill Shardie

**Thoughts:** I am glad to hear that there is a few of us enjoying outstanding longevity. I feel very grateful to be part of such a lucky group. Although he didn't perform my transplant, I was under the care of wonderful Professor Don Esmore and the fantastic team afterwards. I am forever grateful for my new heart, it has allowed me to see my three year old daughter grow into a beautiful young woman and proudly walk her down the aisle last year. I have been able to carry on with my business as a registered carpenter/ builder for the last 28 years.

28

YEARS

### John Winter

**Lives:** Currie (TAS)
**Transplanted:** February 1992 H
**Surgeon:** Professor Don Esmore

**Thoughts:** I had to have a heart transplant due to Eisenmenger's Syndrome (Congenital). I have been able to lead an active, community service life. I am supposedly retired (but no such words exist in my vocabulary). Thank you and very kind regards to all who have helped me over the many years since my transplant. *John (Old-man Winter)*

# TRANSPLANT 2020 ANNIVERSARIES

## HEART

### AUGUST
Neville Eyre 2002
Demir Terziu 2008
Dean Thomson 2009
Thomas O'Driscoll 2012
Domenico de Maria 2014
Glen Jones 2018

### SEPTEMBER
Monty Kleiman 1993
Lloyd Honeycombe 2000
Greg Maroney 2014
Colin Goodman 2016
Scott Moorhen 2018

### OCTOBER
Libero Viola 1992
Robin Oliver 2000
Phillip Felman 2005
John Campbell 2008
Jeffrey Priest 2008
Janet Williamson 2009
David Finlayson 2015

## HEART + LUNGS

### OCTOBER
Clair Stubber 1996

## LUNGS

### AUGUST
John Mills 2008
Sivaraman Sivapiragasam 2011
Stephen Kinson 2012
Phillip Laffan 2015
Nicole Barnes 2017

### SEPTEMBER
Shirley Aisbett 2008
Martina McArdle 2009
Louisa Walsh 2010
Rebecca Berry 2012
Daryl Walker 2012
Angus Harrison 2015
Flynn O'Malley 2015
Gillian Annette Fleming 2016
Warren Stone 2017

### OCTOBER
Jane Fletcher 1993
Janet Johnson 2011
Valerie Ann Shentzer 2011
Judith Hogan 2012
Carol Huxley 2012
Agnes Russell 2014
Nadina Saifert 2014
Andrew Weybury 2015
Gloria Lancione 2015
Kristan Braun 2015
Brendon Foster 2017
Sharon Golden 2017
James Carroll 2017
Michele Cassidy 2019
Annie Greig 2019

## Committee meetings 2020

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

**Meeting 4/4** - *AGM (followed by meeting) Tues 10 Nov, 2020

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

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

## HLTTV Member Events

- **Medibank Melb Marathon**
  The Melb Marathon is now online in December
  **melbournemarathon.com.au**

## Circulator content deadlines

- **Fourth quarter** – Fri 13 Nov

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***We'd love to hear about your experiences pre and post transplant. Everyone is welcome to contribute to The Circulator. Send contributions to circulator@hlttv.org.au***

*Many of our members have had to implement COVID-19 measures to keep safe this year!*

## Alfred transplants and VADs 2020

*Both LVAD and BiVAD included in this figure*

| Heart | Lungs | VADs |
|---|---|---|
| 20 | 64 | 15 |

*Note: these figures are for the period January 1 – October 7, 2020*

GiveNow

**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**

# A mother's love

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

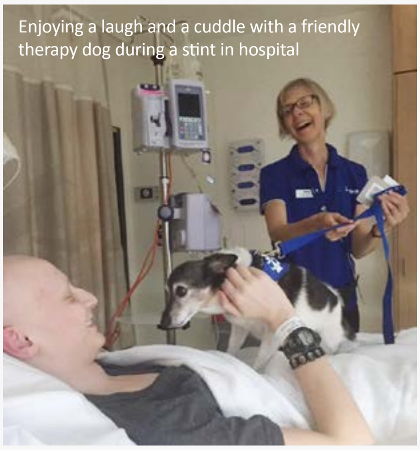
**I met Michelle Richter and her son Kurt just over three years ago when I was in the Alfred undergoing my own LVAD implantation and recovery. She was a typical mum who clearly loved her son, but when I eventually heard the full story about Kurt, I came to appreciate the depth of that bond between them.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

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

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

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

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



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

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

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

Spending time with him was my happy place.

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

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

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

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

The first open heart surgery to insert the BiVADS was 20-7-17. Unfortunately, overnight he had severe internal bleeding from the heart.

The second open heart surgery was 21-7-17, but he experienced a blood clot in his right ventricle which got stuck in the RVAD and it stopped working!

The third open heart surgery to completely replace the RVAD was performed on 24-7-17.

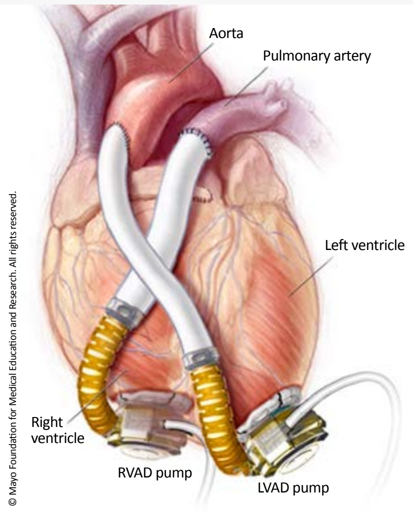
I sat by his bedside in ICU from 7am until 11pm every day for weeks and continued to do so during the following three months on Ward 3E.

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

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

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

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



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

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

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

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

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

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

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

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

As a mother I'm thankful that I can stay at home and be there for Kurt.

As someone who is finding his confidence again, he insists on catching the train and going to Uni to regain his independence and meet new friends.

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

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

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

Kurt exhibiting some of his paintings

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

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

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

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

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

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

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

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

As they say – *new heart... new start!*

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

God bless all the donors and recipients.

**Michelle Richter**

*Before his cancer and subsequent heart failure, Kurt was a cadet in the Royal Australian Airforce. He'd had flying lessons since the age of 15 to earn his pilots licence had his future planned out to leave school after Year 12 and join the airforce. Life is so full of twists and turns. It reminds us we should all make the most of every day.* (Editor)

# Gifts of life keep on giving...

**As a live kidney donor I've had 40 years to witness the miracle of transplantation, but never has that miracle seemed more incredible than now, with the added risks to surgery inherent in the world of COVID-19.**

In our shared battle against the pandemic, it's easy to lose sight of the personal stories of endurance that were there long before we heard the word coronavirus. The inspirational stories of cancer and survival, of tenacity in the face of disability, of lives changed in split-seconds by freak accidents, of people whose circumstances make every single day a triumph of resilience.

One such story, reported in *The Sunday Age (30/8/20)*, talks of *"a gift of hope from the despair of others".* It tells of the vast team of people involved in enabling a Melbourne woman to receive a life-changing kidney, donated by an anonymous young donor from Western Australia.

The fact organ donation has managed to tick along almost unnoticed behind the scenes of COVID-19 is indeed a miracle. The gifted surgeons with their dedicated medical teams, co-ordinators and endless others who work tirelessly in the background to make it happen are the invisible heroes.

Over the four decades since I donated a kidney to my sister, with many years as a volunteer for DonateLife (Vic), I've had the privilege to develop close friendships with inspirational people whose existence is testament to the sanctity of life and the endurance of the human spirit.

Those who live on transplant waiting lists with hospital bags packed ready for the phone to ring, signalling that their time has finally arrived. The renal patients who survive through the relentless hours, weeks, months and often years hooked up to a dialysis machine. Those waiting for lungs whose every breath is a triumph of the machine keeping them alive. The toddlers born with liver disease who can only look on as other children play.

And behind each transplant lies another story. A story of love from a live donor, or a story of selflessness and extreme generosity from a stranger and a family, often at times of profound grief.

Just as those daily COVID-19 numbers are not just statistics, the organ donation rates are wives, husbands, mothers, fathers, sons, daughters, brothers and sisters whose lives have been changed forever. Now more than ever, we need to shout these stories from the rooftops and find faith in the ultimate good of humanity.

**By Janine Joseph**
*Janine is a well known*
*Melbourne writer*

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

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**HLTTV**

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

# AGM

## Notice of Annual General Meeting 2020
## Tuesday 10 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 2019 AGM
2. Presentation of the 2020 Annual Report
3. Presentation of the 2020 Annual Financial Report*
4. Elect officers of HLTTV and the ordinary members of the committee; and
5. Confirm appointment of the auditor for 2020-2021
6. Any special business (if any)

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

The 2020 agenda and minutes of the 2019 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 20 October 2020.**

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

Please email the secretary@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 Secretary via email or hand it to the Secretary 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 6 November, 2020.**

**If you are unable to attend, and would like your apologies to be noted, contact the Secretary, Maarit Moilanen 0400 190 356 or secretary@hlttv.org.au**

**@HLTTV** **www.hlttv.org.au**

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# Join the Ballarat Support Group

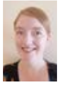
## The Ballarat Transplant Recipient Catch-Up Group is the only group of its type within Victoria.

It provides recipients and their carers the opportunity to obtain information and education from health professionals in a relaxed and informal group environment and is endorsed by the Heart Lung Transplant Trust of Victoria, affiliated with the Alfred Hospital.

Members of the group come from all around Ballarat and surrounding areas. If you live in or around Ballarat and are interested in being part of the group or find out about upcoming meeting dates and locations, please contact:

**Donation Nurse Specialist Larna Kennedy on 0411 323 006 or email her on larna.kennedy@bhs.org.au**

# Resilience: bouncing back against adversity



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

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

***Having a heart or lung condition and/or recovering from treatment (including transplantation) can result in the experience of numerous challenges and setbacks for patients and their loved ones.***

**Commonly within a clinical health psychology session, patients and their loved ones report numerous adversities from the point of the initial diagnosis of a lung or cardiac condition, through treatment and beyond.**

These adversities may be triggered by numerous lifestyle changes including; understanding of the diagnosis and prognosis, the management of numerous medications, coping with fluid restrictions and dietary changes, shortness of breath, uncertainty about future treatments and waiting periods as well as reduced engagement or ability to engage in activities of interest and pleasure.

As a result, it is usual when faced with adversity, to experience heightened anxiety or low mood. We might feel our resilience to be lowered and as a result we may experience increased emotional pain and stress. The good news is that anyone can build their resilience as this is something that can be learnt and strengthened. It involves various behaviours, thoughts and actions that anyone can learn, however with intentionality and practice.

**You might ask... how do I build my resilience even when faced with adversity? I would say it involves the following key steps:**

- **Connection to others:** Not only your loved ones, however it is critical to building resilience and to be able to bounce back against adversity to reach out and connect with others who have experienced a similar health issue and who can understand your experience as well as validate this. With your loved ones, it might also be important to revisit activities that you enjoyed doing together before your diagnosis and to make time to engage in an activity that is non health related that you enjoy with your loved ones at least once a week. This is especially important during waiting times or periods of uncertainty surrounding your health or that of your loved one.

> **Resilience is the process of adapting in the face of adversity, trauma, tragedy, threats or significant sources of stress — such as family and relationship problems, serious health problems, world events/disasters or occupational and financial stressors.**
>
> ***American Psychological Association, 2020***

- **Take care of you:** Make an appointment to look after yourself each day, even for a short amount of time as this can be an important way to build resilience and recharge during difficult times. This self-care or 'you time' appointment can be something that takes a few minutes (such as listening to your favourite song, practicing mindfulness, stretching) or longer (such as doing an act of kindness for someone, doing some gardening, or trying something new such as a new hobby).
- **Define your purpose:** Despite adversity and what is happening with your or your loved one's health, you are still living. Therefore, it is really important to have some goals and a purpose so you have a focus for each day, regardless of your or your loved ones health status. Ideally your purpose represents something that you strongly value. Consider what's most important to you and set some goals around this. Or reflect on a time you were doing something that brought you enjoyment and where the time passed by quickly, what was it about the activity that you most enjoyed? Can you engage in this again or in something new that also gives you the same sense of enjoyment? How can you do something now that also taps into this and defines your day rather than health? Consider what the adversity has helped you with and what can you discover about yourself from this setback as a way to define your purpose.
- **Embrace helpful thoughts:** Remind yourself, like previous life adversities that "this too will pass". It is usual to feel overwhelmed by a set back and to have catastrophic thinking that this is the end. Try and manage this by checking the facts. Also by practicing self-compassion by reminding yourself that while you cannot change the situation, you can change your reaction to it. Notice if you are struggling with an issue and how much time and energy this might be taken from you. Try and sit with the struggle and imagine defusing it, buy letting the struggle go.

A good way to do this is to write it down and then put it away and come back to it on a brighter day. Reflect on past adversities and what has helped you during these times such as resources and people. Look at how you might be able to draw on this support or similar support and resources again.

**Speaking to someone whether it is a friend, family member, counsellor or psychologist is a great way to unload stress and to build your resilience. There are also helplines available to speak to someone at any time:**

**Lifeline: 13 11 14 available 24/7**

**Beyond Blue Coronavirus Mental Wellbeing Support Service: 1800 512 348 available 24/7**

# Osteoporosis is something we should all take seriously

*Post-transplant anti-rejection medications can have a negative long-term affect on a recipient’s bone density leading to osteoporosis.*

**Osteoporosis affects both men and women. It is a common disease affecting over 1 million Australians and makes bones become brittle leading to a higher risk of breaks than in normal bone.**

Osteoporosis occurs when bones lose minerals, such as calcium, more quickly than the body can replace them, causing a loss of bone thickness (bone density or mass).

As bones become thinner and less dense, even a minor bump or fall can cause a serious fracture. A ‘fracture’ is a complete or partial break in a bone. Any bone can be affected by osteoporosis, but the most common sites are the hip, spine and wrist. Fractures in the spine due to osteoporosis can result in height loss or changes in posture.

Normal bone

Osteopenia

Osteoporosis

Severe osteoporosis

Osteoporosis usually has no symptoms until a fracture occurs this is why osteoporosis is often called the ‘silent disease’.

Anyone with specific risk factors for osteoporosis should be investigated by their doctor. Anyone over 50 who experiences a broken bone from a minor bump or fall should be investigated for osteoporosis.

Fractures can lead to chronic pain, a loss of independence, disability and even premature death - so managing bone health to avoid fractures is a priority.

### ACT EARLY TO STAY STRONG

**Transplant recipients need to have a plan in place to monitor bone density. This is due to anti-rejection medications affecting the way your body absorbs calcium which is important for bone strength. Work closely with your medical team to have regular bone scans, and act early to support your quality of life.**

### ARE YOU GETTING YOUR FILL?

**There is a wide variety of foods rich in calcium, including: milk, yoghurt, cheese, eggs, cruciferous vegetables, spinach, broccoli, kelp, ocra, sardines, soybeans, white beans, orange juice, rainbow trout, kale, bok choy, almonds, salmon, sesame seeds, chia seeds, tofu, and soy milk.**

## Stop the fracture cascade

The risk of future fractures rises with each new fracture - this is known as the ‘cascade effect’. For example: women who have suffered a fracture in their spine are over 4 times more likely to have another fracture within the next year. It is essential that osteoporosis is diagnosed and treated to prevent further fractures.

## Risk Factors

- Both men and women may have certain ‘risk factors’ that can make them more likely to develop osteoporosis. People should discuss risk factors with their doctor, and anyone over 50 with risk factors may require a bone density scan.
- Women are at a greater risk of developing osteoporosis because of the rapid decline in oestrogen levels during menopause. When oestrogen levels decrease, bones lose calcium and other minerals at a much faster rate. As a result a bone loss of approximately 2% per year occurs for several years after menopause.
- Men also lose bone as they age, however testosterone levels in men decline more gradually so their bone mass remains adequate till later in life.

### Your family history

Bone health can be strongly inherited so consider your family history of osteoporosis. It is important to note if anyone in your family (particularly parents or siblings) has ever been diagnosed with osteoporosis, broken a bone from a minor fall or rapidly lost height. These can indicate low bone density.

### Your calcium and vitamin D levels

- Low calcium intake – adults require 1,000 mg per day (preferably through diet) which increases to 1,300 mg per day for women over 50 and men over 70
- Low vitamin D levels – a lack of sun exposure can mean you are not getting enough vitamin D which your body needs to absorb calcium

### Lifestyle factors

- Low levels of physical activity
- Smoking
- Excessive alcohol intake
- Weight – thin body build or excessive weight (recent studies suggest that hormones associated with obesity may impact bones).

### Your medical history

Certain conditions and medications can impact on your bone health.

- Corticosteroids – commonly used for asthma, rheumatoid arthritis and other inflammatory conditions
- Low hormone levels – in women: early menopause; in men: low testosterone
- Thyroid conditions – over active thyroid or parathyroid
- Conditions leading to malabsorption eg: coeliac disease, inflammatory bowel disease

- Some chronic diseases eg: rheumatoid arthritis, chronic liver or kidney disease
- Some medicines for breast cancer, prostate cancer, epilepsy and some antidepressants.

## Why Calcium Is Important

Your bones serve a structural role, but they are also your body's main reservoirs of calcium, which has multiple essential functions in the body.

Your body maintains blood levels of calcium within a narrow range. If you're not getting calcium from the diet, your body pulls it from your bones to sustain other functions that are more important for immediate survival.

Some amount of calcium is continually excreted in the urine. If your dietary intake doesn't compensate for what is lost, your bones will lose calcium over time, making them less dense and more likely to break. There are many foods that are calcium rich.

## How is osteoporosis diagnosed?

Osteoporosis is diagnosed with a bone density scan (commonly known as a bone density test). It is a simple scan that measures the density of your bones, usually at the hip and spine.

You simply lie flat on a padded table and the arm of the machine passes over your body. The scan takes approximately 10-15 minutes. You remain clothed during the scan. Your GP will first assess your risk factors for osteoporosis before referring you for a test.

## Who should have a bone density scan?

Men and women over 50 with risk factors may need a bone check up with a bone density scan. If your bone density is low, you are more likely to fracture a bone in the future. Some risk factors may also require people under 50 to have a bone density scan.

The sooner you find out if you have low bone density or osteoporosis the better, you need to know as early as possible to manage your bone health.

Finding out this information means you and your doctor can take action to keep your bones strong, slow bone loss and reduce the risk of breaks.

## What will the result tell me?

A bone density scan will determine if any action is needed to improve your bone health – normal; low bone density (called osteopenia) or osteoporosis.

www.osteoporosis.org.au

# A cautionary tale about the milkman...

**Meet Gordon Miller – he likes milk bottles and he likes milk. In the country town where he used to live, the town water was often funny tasting and the tank water was no better, so in his early youth he drank milk almost exclusively.**

When he finished school and became an apprentice, he could afford to drink milk all day and so he did. It didn't matter if it was plain milk, low fat milk, or flavoured milk, he would regularly drink four litres per day (perhaps he should have learned to drink beer, coca cola, or coffee like all his workmates).

After finishing his trade he changed paths and spent a lot of time working in dairy sections of supermarkets where the milk was free so long as he could return the empty "leaking" milk cartons. He eventually ended up working for various cheese companies where his seemingly insatiable pursuit of dairy products was never really satisfied but he still got more than his fair share of dairy.

So he was extremely surprised to find out during his heart transplant work-up that he had osteoporosis *(milk for strong bones he was told as a youngster).* When he questioned his cardiologist, he was informed that it was probably the 10 years of taking diuretics between his initial heart failure and being listed.

From there it was off to the hospital to consult with the endocrinologist who gave him an infusion of *Zoledronic acid,* told to take a Vitamin D and Calcium supplement and come back in a year for a bone density check.

As far as he was concerned he was fixed and was only taking Vitamin D and Calcium supplements to keep his doctors and favourite nurses happy. After a few months he decided that the Calcium and Vitamin D tablets had a texture he didn't like and maybe he didn't 'really' need them. After all, he was drinking milk (not four litres per day though), doing weight bearing exercises at the gym and obviously, everybody in Australia gets plenty of Vitamin D from the sun don't they?

Then after 15 months post-transplant he went for a planned check up with his cardiologist who enquired if he had undergone a bone density test recently. *"Of course not"* he told him, *"I'm not taking diuretics anymore."* His cardiologist went on to tell him that T*acrolimus* (one of his anti-rejection drugs) also had an effect on bones.

So trying to appear as compliant as possible, he went off and had a bone density scan confidently expecting that he would be fine. At the next appointment with his cardiologist he was sent back to the endocrinologist and another infusion of *Zoledronic acid.*

After that infusion he met another transplant recipient at his local pub who was twenty-two years post and had a 3D-printed vertebrae inserted in her spine because of osteoporosis and she was convinced it was the medication that caused it.

He has since broken his little toe, accidentally kicking a door frame, and consequently received no sympathy from his wife at all.

His milk bottle collection is growing, and he's now taking his cardiologist's advice about taking Vitamin D and Calcium supplements.

He has, at last, come to the conclusion that medical advice is crucial to his long-term well-being and will listen carefully to, and compliantly follow, that advice.

A great choice to make Gordon!

---

**Get with the program – your second chance at life depends on it!**

Post-transplant life can be tough. New medication regimes can be hard work when we want to feel back in control of our life. When we feel well, that's when it's most important to *'stay with the program'.* It's important to trust our post-transplant medical team advice. Not only do they have decades of research guiding them, they're committed to keeping us well during our second chance at life.

Gordon received his new heart in 2018 and is building quite a collection of old milk bottles

# Managing your skin after transplant is vitally important

## *Life post-transplant requires an adjustment to diet, hygiene, infection control and lifestyle in particular to balance a range of ongoing risks.*

By Bruce McAndie

**Bruce McAndie underwent a heart transplant at The Alfred in 2018. In this article, he writes about the need for constant vigilance about the condition of your skin in order to mitigate the increased risk of skin cancer due to anti-rejection drugs.**

After my heart transplant I received education in a number of topics from the hospital educators/specialist staff.

One of the topics that surprised me was the impact of the anti-rejection drugs on the likelihood of getting skin cancers.

*"Patients who have received an organ transplant have a higher risk than normal for developing skin cancers, in some cases up to 65 times the risk, compared with non-transplant patients. In particular, transplant recipients have a significantly increased risk of developing squamous cell carcinomas".*

Ref: DermNet NZ

In researching a bit more around the topic I decided to focus on *tacrolimus* and *mycophenolate* – the particular drugs I am on to prevent organ rejection.

*"**Tacrolimus:** Transplant patients have an ~100-fold increased risk of developing cutaneous squamous cell carcinoma than the general population and are also at an increased risk of developing basal cell carcinoma, melanoma, Merkel cell carcinoma and Kaposi's sarcoma".* Ref: DermNet NZ

*"**Mycophenolate:** Mycophenolate may increase your risk of developing certain types of cancer, including lymphoma (a type of cancer that develops in the lymph system) and skin cancer. Avoid unnecessary or prolonged exposure to real and artificial sunlight (tanning beds, sunlamps) and light therapy and wear protective clothing, sunglasses, and sunscreen (with a SPF factor of 30 or above). This will help to decrease your risk of developing skin cancer".*

Ref: MedlinePlus (US National Library of Medicine)

**Preventative measures, early detection, regular skin checks and appropriate early treatment of skin lesions are essential to minimise the harm caused by these cancers.**

### So, how do I manage this whole thing around skin cancers?

**Checking and Managing**

In my case, I have six monthly dermatology checks looking specifically for skin cancers. I have had a number of skin cancers removed over the last two years. Most of these have been basal cell carcinomas (BCC's), which are not too bad in the scheme of skin cancers but, if left unchecked, can certainly become an issue.

I have also had a squamous cell carcinoma (SCC) removed. SCC's are more of an issue than BCC's and generally need to be dealt quickly. My skin doctor tells me that sometimes they can treat lesions with topical creams or cryogenic freezing. As it turns out, they have taken a more aggressive approach for me and have excised all lesions – leaving a clear margin around the lesion. I understand that removal seems to be the preferred option for transplant patients. I figure that another scar is better than the alternative if a skin cancer is not managed well.

### How do you check if you have a skin cancer?

I keep a check myself looking for any spot that is unusual, new or changing in appearance. If I see something that is suspicious then I have it checked regardless of whether it is within the six month appointment schedule.

Don't underestimate the importance of someone else checking you out! My wife noticed something behind one of my ears that I had not noticed – it turned out to be an SCC (so how was I ever going to see that myself)?

### How do I manage on a day-to-day basis to minimise the possibility of getting skin cancers?

Firstly, after my morning shower I apply 50+ SPF UVA and UVB sunscreen lotion. I wear clothing that affords me good protection (i.e. long pants/sleeves and legionnaire style hat).

There are lightweight clothing options available that are suitable for the warmer weather, so you can still stay sun protected while outside (e.g. Fisherman tops and other branded clothing providers who advertise 'sun-smart' products e.g. Solbari). I aim to make no exceptions to this routine.

When it comes to walking exercise, I go out predominantly very late in the afternoon or, often, when the sun has gone down. Some people might prefer to catch the early mornings – although it can be a beautiful time of the day, for me, I function better later in the day! Regardless, the idea is to minimise direct exposure to the harmful UV rays.

### Why are transplant patients at higher risk of skin cancer?

Transplant patients require the long-term use of immunosuppressant medications to prevent organ rejection, but they impair the capacity of the immune system to repair or destroy UV-damaged cells, allowing these damaged cells to develop into cancers.

Skin cancers are often very aggressive in transplant patients and are associated with a high risk of metastases (spreading) and recurrence. It is important that any skin cancer is treated at an early stage to minimise this risk.

Most skin cancers in transplant patients are treated by surgical excision or Mohs micrographic surgery. Surgery allows the specimen to be examined by the pathologist to ensure that the cancer has been completely removed. In some cases, further surgery or radiotherapy may be required. Occasionally, some lower-risk skin cancers, such as small tumours on the trunk may be treated with electrodesiccation and curettage.

Melanoma can be very difficult to diagnose in organ transplant recipients, leading to a low threshold to excise any unusual or changing lesion. Melanoma tends to be thicker and more advanced on diagnosis than in non-transplant patients, and these tumours may behave aggressively in organ transplant recipients.

#### SOME IMPORTANT STATISTICS

- The Australian Institute of Health and Welfare estimates that in 2020 there will be 16,221 new cases of melanoma of the skin diagnosed in the general population in Australia.
- Estimated deaths from melanoma will be 1375 (891 men and 484 women).
- Melanoma was the 4th most commonly diagnosed cancer in 2016 in Australia.
- In 2016 there were 14,485 cases of melanoma diagnosed. In 2020 it estimated to be 16,221.

Some common skin cancers:


BCC Affecting the Trunk


BCC affecting the Nose


SCC affecting the Limb


SCC affecting the Face


Superficial spreading Melanoma

Australian Government
Australian Institute of Health and Welfare
AIHW

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# 31 years later...

*I am inspired and amazed at the capacity of people to fight and survive and I am sure this determination plays a key role in recovery.*

**Born on Christmas Day, 1936, it has been 31 years since Edward O'Bryan's Heart Transplant in March 1990 and the following is an excerpt from a story he wrote after his 20th Anniversary post-transplant.**

*In sharing my own personal reflections I hope that my thoughts can be of support to others.*

*People awaiting a heart or lung transplant look death in the face. It is a humbling experience and I am sure everyone contemplates the meaning of life. For me it was a time when I reflected on my life.*

*Now when I read stories written by heart/lung transplant recipients, it is clear to me that these stories come from real people who have looked beyond their troubles even when the going seemed impossible. They have made the best of their situation, climbing back up and starting life again.*

*In Melbourne all transplant patients receive the strongest support and encouragement from the Alfred Hospital. I notice that in addition to always acknowledging the hospital, transplant recipients give unstinting praise to the organ donors and loved ones who have given them support during their ordeal. I am inspired and amazed at the capacity of people to fight and survive and I am sure this determination plays a key role in recovery.*

*Both my parents lived into old age. I am now in my seventies, the second youngest of six children all of whom still live productive lives. My eldest sister is well over eighty and enjoys good health. Until the age of fifty-three I had not had a day's sickness in my life and I was dumbfounded when I was told that I had cardiomyopathy.*


Sue and Edward O'Bryan celebrating 31 years of post-transplant life together

*The cardiologist who diagnosed my illness, the late Dr. William Heath, was a family friend. Both his parents had died when he was a teenager. He brought up his younger siblings in the country and after qualifying as a doctor he ultimately reached the top of his profession. He left a lasting impression on me during my illness by emphasising that with courage and determination adversities which look insurmountable can be overcome.*

*When I had been feeling unwell and first visited Dr Heath, I was running an engineering company which operated in Australia, New Zealand and South East Asia. I had founded and built this business over thirty years. I mention this because receiving the news that I was unwell, not only came as a shock but as a huge challenge to deal with this business which I had established. At the time I had four children the youngest only one. I believe that it is those who love us who go through the greatest trauma in all this. In my case, my wife never showed her distress but always continued the daily routine as if life was normal. She did so many things for me to occupy those long drawn-out anxious days of waiting.*

*In due course I was accepted on to the waiting list for a heart transplant. For a period of about nine months I was largely confined to my bed. Anyone awaiting a transplant will find this a debilitating time. I developed shingles. To this day I still have chest pain resulting from that virus. There were times when without the incredible support given to me by my wife and by Dr Heath, who called on me almost daily, I would have found it difficult to pull through. He had many stories to tell which brightened my day and when I now look back I remember those stories and realise how very small things that we do in support of others in their time of need, can make a great difference.*

*Listening to the radio one day while lying in bed I heard of a Scottish immigrant who had started a factory in Altona making haggis. I had never tasted a haggis and my wife telephoned the owner. She explained my condition asking at the same time if she could drive me out and see the factory. The owner gave me a wonderful tour of all stages of manufacture and then presented me with a haggis free of charge for my dinner.*

*Waiting for my transplant I had mixed emotions. On the one hand I was desperately waiting for the telephone to ring knowing full well that time was running out; on the other, every time it did ring I was too timid to answer it in case it was the real call from the Alfred. It was only on my third call and visit to the Alfred that the operation took place. The first two occasions were unpleasant experiences when it didn't turn out to be my chance.*

*On the third occasion it was late in the afternoon that the hospital telephoned. All that day I had been looking forward to a special dinner being prepared by my wife and of course I was told that I could not have any food as I was required in the hospital in a couple of hours time. At the Alfred I had been fully prepared for the operation when the anaesthetist said to me that I could be in for a wait. He asked me to relax and to take my mind off the impending operation tell him about something which I had been doing recently. Of course there wasn't much to say but I did notice that he spoke with a Scottish accent and so I decided to tell him about my visit to the haggis factory. Some days after my operation, my wife showed me the Herald-Sun which had published my haggis story given to the newspaper by my anaesthetist.*

*A family friend of Greek nationality, familiar with the hospital system in Greece where patients supply their own food, had prepared meals for my stay at the Alfred. The food was left in the staff-room refrigerator with my name on each dish, a meal of grilled whiting, another of duckling, rare beef, chicken, together with a variety of all different deserts and cheeses. I was told by the nurses that my food had filled their refrigerator. I was very limited in what I could eat and I was teased by the nurses. They would come into my room each day and tell me how much they were enjoying each dish and especially the deserts and cheeses.*

*It was my first stay in a hospital and I must say the early hours of the morning were a hard time for me as a trolley would pass my bed at about four o'clock. I was sure that on the trolley was the body of a person who had died during the night, being then taken out draped in a sheet. I tried to use the trolley with the body as an excuse to get out of the hospital but I was told that the trolley only contained dirty linen from the night shift. I was anxious to get out of the hospital in time for my daughter's third birthday but it was quite a battle with Dr Esmore. Finally he allowed me to go and I did make my daughter's third birthday party. The wonderful but cautious Dr Esmore, who we all hold in the highest regard, achieved a world record with me. I was up and out of the hospital in ten days able to resume normal life.*

*My youngest daughter who is now sixteen was born five years after my transplant. The Transplant Clinic gave my wife and me a warm welcome on my visit to the Alfred after the birth.*

*Post transplant I have enjoyed an active and wonderful life with my wife and children. To people awaiting transplant who might read my story, remember that the greater the challenge you overcome in your life, the greater your reward. Stay strong and focus on your future beyond transplant surgery.*

*Twenty years on, when I take my medication, I remember the generosity of my donor family and think of those living through the same trauma that I experienced not so long ago.*

*Edward O'Bryan*
*Port Fairy, Australia*

**Responding to my call-out for member contributions to the Circulator, Edward generously reached out with his story and has followed up with some further words to bring us up-to-date with his incredible and inspiring journey of three decades of post-transplant life.** Editor

*I am now approaching 31 years post heart transplant and I am sorry to say that even though my heart is in excellent shape, the last few years have been very challenging as a result of severe and chronic neuropathic pain in my feet.*

*There is no treatment for this condition but prior to it coming on Sue (my wife) and I managed to steer our three teenage girls through life and university and we now have two lawyers and one clinical psychologist in the family. Two of our daughters are married and a grandson was born three weeks ago.*

*We were also lucky to have a couple of overseas trips and to see all of our own country Australia during the last 10 years. We have travelled north to south and east to west. We travelled along Len Bedell's Gun Barrel Highway to the west coast of Australia, up the west coast of Australia through the Kimberley to Darwin and visited the Tiwi Islands, on the Ghan from Adelaide to Darwin from Port Augusta, from Darwin to Jabiru and East Arnhem land, up the east and west coast of North Queensland to Thursday Island.*

*I turn 84 in a few months time and I think constantly of the generosity of the anonymous donor who gave me my heart, the expertise of my surgeon the late Don Esmore and the support of the Alfred Hospital transplant team who have given me such an incredible gift of life for the past 31 years.*

*Above all else, I have received the love and support of my partner in life, Sue, who has lived every minute of this journey with me.*

**See page 10 to read about Edward's heart surgeon – the late Don Esmore AO**

***To you who have received a transplant or are waiting to have one my message is clear – try to do better than me! Life is so special and your heart transplant fulfils one of the great virtues in life – hope, your hope, to continue living.***

# HLTTV Second Chance Accommodation Program

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

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

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

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

## Park Regis Griffin Suites

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

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

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

# The HLTTV provides a wide range of support

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

**Our services and programs include:**

## Second Chance Accommodation Program (SCAP)

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

## Donations to The Alfred

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

## Fitness Grants

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

## Emergency Financial Assistance

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

## Heart to Heart Respite House (Barmah, Vic)

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

## Information and support about transplants and organ donation

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

## Peer Support

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

## Social events for members of the heart and lung transplant community

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

## Visit us at www.hlttv.org.au

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

# Your membership counts

## Heart and Lung Transplant Trust (Victoria) Inc

### PERSONAL DETAILS

Name Partner's name (if applicable)

Address Postcode

Postal address Postcode

Telephone Mobile

Email Date of birth

### NEW MEMBER

I wish to become a member of the Trust ☐

### EXISTING MEMBER

I wish to renew my membership ☐

### *CIRCULATOR* NEWSLETTER

I wish my copy to be emailed ☐

I wish my copy to be posted ☐

### MEMBERSHIP TYPE

### *RECIPIENT*

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

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

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

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

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

**Signature** Date

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

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

Please return this form to:
**Membership Officer, Heart and Lung Transplant Trust (Victoria) Inc**
**PO Box 25036**
**Melbourne 3004 Victoria**

HLTTV

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

# let’s talk organ donation

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

donatelife