

the Circulator

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

Winter Edition | 2019 | Issue No. 96



HLTTV

*Our vision is for a
bright and active
future for all those
involved with or in
need of a heart or
lung transplant.*

GRAB YOUR TICKETS NOW
for the HLTTV's 25th Anniversary Gala!
Saturday 31 August 2019
BAYVIEW ON THE PARK, 52 QUEENS ROAD, MELBOURNE

President



HLTTV Committee at the recent HLTTV BBQ

A warm welcome to an already very cold winter to all our existing and new members, and new readers.

I've already had a few bracing days watching my kids play their winter sports in frost and mud, and these activities have reminded me about the sense of belonging, achievement and connection we get from being part of a community activity.

In junior footy, it takes a dedicated core of volunteer family members to get the team 'on the ground' and keep everything ticking. It's the same for our HLTTV activities, whether it's this newsletter, our *Second Chance Accommodation Program*, or social events like our 25th Anniversary Gala on Sat 31 August, 2019 (which is going to be AMAZING!).

These activities, and many more, are only possible due to the work of a group of volunteers – all of whom work other jobs (many of them full-time) but are driven to create a sense of connection, belonging and support for those of us on the transplant journey.

Maarit, Martina, David, Vanessa and I have been thrilled to be joined by a few new faces over the past few months – the Circulator has received a new lease of life thanks to the talents of Graeme K. and we're already seeing the work of Adam M. across our social media channels.



One of the great activities at the HLTTV BBQ

We loved seeing so many of you at our glorious Easter BBQ in April. This always standout event was taken to a new level this year with the addition of some fabulous activities hosted by committee members and their supporters, and many reminders of HLTTVs 25th Anniversary milestone (including delicious cupcakes!) Sincere thanks to the many, many contributors who made the day such an enjoyable one.

The Easter BBQ reminded many of us about the incredible contributions and impact made by past committee member and Vice President Camille Condon, who sadly passed away in April. This edition features reflections from past President Louisa Walsh, who speaks for many of us in highlighting just how much Camille is very missed and very loved. Generous and thoughtful even during her toughest times, Camille organised or inspired close to \$5000 of fundraising for HLTTV. We love you Cam.

So now all there's left for you to do is [buy tickets to the HLTTV 25th Anniversary Gala](#) – tickets are still only \$75, which includes entertainment and a delicious three course meal, soft drinks, tea and coffee.

Visit www.trybooking.com/BCAQF to buy tickets – look forward to seeing you there!



Belinda MacLeod-Smith
President, HLTTV

Wonderful generosity

The Committee would like to thank all of those who have generously donated over the 2018-19 financial year. Many of our members customarily add donations to their subscriptions and are probably too numerous to mention, so a collective THANKS to all of you who continue to support us, we couldn't do it without you!

We also received some sizeable donations before EOFY – if you have not received your tax receipt from David and need one, please chase him up directly at treasurer@hlttv.org.au, he just loves e-mail!

Sadly we also lost some good friends this year. Thanks to all who contributed in the memories of Camille Condon and Graeme Percival.

A call out for Kirsten Dewitt, whose jewellery sales raised over \$2000 in memory of Cam.

We also received a number of other legacies, thanks to all of you who supported... in memory of loved ones.

Committee meetings 2019

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

Meeting 3/4 - Tues 13 Aug, 2019

Meeting 4/4 - *AGM (followed by meeting) Tues 12 Nov, 2019

Meetings are usually held at the Alfred, Fifth Floor Meeting Room at 7.30pm with the Committee meeting in Alf's Café at 7pm for a catch up. ALL WELCOME!

Events

- **HLTTV 25th Anniversary Gala**
Saturday 31st August, 6.30pm
Bayview on the Park
52 Queens Road, Melbourne
Purchase your tickets at www.trybooking.com/BCAQF
- **Christmas BBQ**
Sunday 24 November 2019

Secretary

After a sunny afternoon at my niece's footy the rain is coming again. Well that's winter in Melbourne.

Hello everyone,

I hope you are all well and sitting somewhere warm – maybe even up north!

The Secretary business has rolled along with enquiries, reports and accountability requirements fulfilled. We had a small Committee meeting in February, with our 5 elected Committee members but an even better one in May, with 3 new members joining the Committee. We have also had extra offers of help for events from other people too.

We gladly welcome Graeme Klemm as General committee member and Circulator editor; whose previous edition of the Circulator has had many positive comments.

Adam Miller has offered his expertise in Communications, so look out for more HLTTV social media posts very soon. Sam Ira, who is heading off to the World Transplant Games and is a film maker, has also joined the Committee.

We also welcome offers of help from John, Anna and Petra, who will help gather some prizes and assist with setting up at HLTTV Events. Plans are well on the way for our 25th Anniversary Gala, being held at the Bayview on the Park on Saturday 31st August.

The Band is booked and venue and theme of silver, black and white, organised. This will be a fun night of dancing and dinner celebrating HLTTV's wonderful 25 years! Book your tickets early so you don't miss out!

We are now looking for some fun and exciting prizes for our main fundraising and celebration event.

If you can help with any donations or have contacts for prizes, big or small, please contact me for a letter of request if you need it. We will have a Live Auction, many Silent Auction items, a Raffle and some fun games across the night.

The Gala is our major fundraiser for this year, and supports the many services provided by HLTTV, including the *Second Chance Accommodation Program*, Fitness and Welfare Grants, and the Social Work Support position at the Alfred.

A quick *thank you* to Jose Lopez for sending us a copy of the Alfred Transplant Association's Newsletter – *Flowing Fresh* (see page 16), from June 1993. It was a fun read! I wonder how the statistics compare now?

If you have any historical information, stories, anecdotes, memories from across the 25 years, please get in contact so we can share them.

Stay well everyone, and hope to see you at the 25th Anniversary Gala celebrations in August.

**Maarit Moilanen
Secretary**

IMPORTANT DATE TO REMEMBER

Membership renewal 2019–2020

HLTTV membership fees are due on 1 July 2019 for the 2019–2020 financial year. There are several payment options: cheque, Paypal or EFTPOS and you can renew online. Details available on the HLTTV website:

<http://www.hlttv.org.au/about-us/renew-membership>

Your \$15 membership fee will greatly assist HLTTV to continue their wonderful work supporting heart and lung transplant patients.



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[Finsbury Green](#)

An inspiring leader

Professor Marasco did work experience in plastic surgery, little wonder she's well known by her patients as an 'artist' for her stitching!

The Alfred are blessed with teams of people who sit at the pinnacle of world health provision, with exceptional skill, experience and passion. This column features one of them – Professor Silvana Marasco MBBS MSurg FRACS MBioeth PhD – Deputy Director Cardiothoracic Surgical Unit at the Alfred.

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

I think I was always going to do a surgical specialty. I have always loved making things and doing things with my hands. I also did work experience with a family friend who was a plastic surgeon, so for quite a while I was focussed on doing plastic surgery.

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

I did see a documentary on TV – I think it was about Fred Hollows – he was removing the bandages from a man's eyes after he had done (I assume) cataract surgery. The man could see and started crying. I think I was about 14 or 15. It had such a profound effect on me. I thought 'gosh I wonder if I could do that sort of work'. Funnily enough, ophthalmology never appealed when I got to medical school.

Can you give some examples of how technology or innovation has improved surgical techniques in recent years?

Cardiac surgery seems to be in constant evolution. The most recent example of that is the development of trans catheter aortic valve implantation which delivers a new aortic valve into position on a catheter without having to open the chest.

Transplantation outcomes have greatly improved during the last decade, where do you see the greatest improvements in the next 5 to 10 years?

The immunosuppressant drugs are constantly evolving and improving. That really is the key to successful transplantation over the long term. The use of xenotransplantation (non human organs)

Q&A

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



Professor Silvana Marasco is Deputy Director Cardiothoracic Surgery and Transplantation and a Cardiothoracic Surgeon at both The Alfred and Epworth hospitals in Melbourne.

She is currently the Deputy Director of the CJOB Cardiothoracic Unit at The Alfred.

Professor Marasco performs the full spectrum of adult cardiac and thoracic operations, including heart and lung transplants and implantation of mechanical assist devices.

Her surgical areas of interest include minimally invasive valve surgery, innovative techniques, and management of chest trauma.

She has a Master of Surgery, Master of Bioethics, a PhD and has published over 100 peer reviewed journal articles and 10 book chapters.

Her research interests have focussed on chest trauma, transplantation outcomes and innovations in surgical techniques for which she has received over \$6million in total funding.

has been talked about for two decades but still doesn't seem to be close.

What role has mentoring played in your career?

Prof Don Esmore has really been my main mentor through the early part of my cardiac surgical career. He was a larger than life character and really made such an impression on everyone who worked with him. A lot of staff still quote him in theatre.

You are a prolific writer of journal articles and book chapters. Why is this a priority for you?

I think it is my duty to do research. I don't think you can just reap the benefits of a medical specialty and not give back. This is my way of giving back to a surgical area that has given me immense satisfaction and fulfilment.

Being a writer yourself, are there particular authors/genres that you enjoy?

I used to love science fiction – and I mean I loved it! But now I rarely have time to read. I tend to just read anything that I am given and usually just when I am on holiday.

You clearly love what you do – what career achievements have given you the most satisfaction?

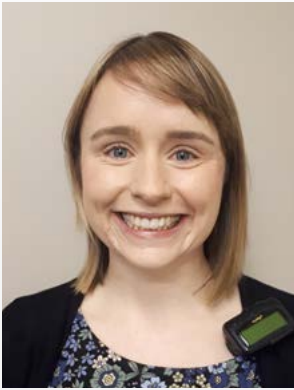
Everything! When I was in secondary school, I would never have imagined that I would be a cardiothoracic surgeon, and a Professor. Coming from a family with no medical background at all, I am just so grateful that I was given the opportunities that allowed me to get where I am today.

You have many commitments in your current role. Is there anything in particular that helps you balance your administrative v surgical v research responsibilities?

Hmm I think I could do that a lot better if I was better at the art of delegating.

The surgeries you do can be incredibly long and complex. How do you take care of your own wellbeing before and after?

Always coffee beforehand – and there is nothing like a cuddle from my two (primary school aged) children to help me recover after.



My name is Maeve Tuohy and I'm a dietitian working with the Heart Transplant team at the Alfred Hospital in Melbourne. Dietitians assist in the nutritional management of patients at various stages of their transplant journey.

This can range from assessing and educating patients upon diagnosis of heart failure, lung disease and respiratory failure, along with maximising their nutritional status before and after insertion of a Ventricular Assist Device (VAD) for heart patients, or around the time of transplant.

Each patient presents unique nutritional challenges. Our role is to maximise our patients' nutritional status pre and post-transplant, and provide education to help them meet their nutrition goals. Optimal nutrition plays an important part in recovering from surgery, keeping new organs healthy and maintaining long term health.

Optimising your nutrition before and after transplantation

There are a number of common nutritional issues which can affect patients at different stages after their transplant and which we discuss with all of our patients in the postoperative period.

Excess weight gain

ISSUE 01

This can occur for a number of reasons. The medication prednisolone may increase your appetite. Your body may also require less energy to function than it did before your transplant. Rapid weight gain or being above the healthy weight range can place too much pressure on your new organs, as well as increasing the risk of other complications such as high blood sugar levels, high cholesterol and high blood pressure.

We recommend checking your weight at least weekly (unless advised otherwise by your medical team). If you are concerned then please discuss with your dietitian.

High blood sugar levels

ISSUE 02

Some immunosuppressant medications, including steroids (prednisolone) can cause high blood sugar levels. This can result in the development of Steroid-Induced Diabetes.

Controlling your blood sugars is important, as high levels can increase your risk of infection, slow your recovery and increase your risk of diabetes complications in the future. Your blood sugars will be checked regularly in hospital after transplant.

Maintaining a healthy lifestyle both pre and post transplant can help to keep blood sugar levels under control.

High lipids

ISSUE 03

Lipids are types of fat which are found in the blood and include Cholesterol and Triglycerides.

High blood lipid levels (hyperlipidaemia) can increase your risk of heart disease and stroke. After transplant, the medications you will be required to take may increase your cholesterol and triglycerides.

Choosing healthy dietary fats (unsaturated fats such as oils, nuts, seeds, olive oil-based spreads and margarines) more often than saturated fat sources (red meats, butter, cream) can help to keep these lipid levels well controlled.

Bone health

ISSUE 04

Steroids can weaken the structure of your bones and increase the risk of fractures, a disease known as osteoporosis. You will have bone scans before and after your transplant to measure how strong your bones are.

Calcium and vitamin D are essential nutrients in keeping your bones strong and healthy. The best dietary sources of calcium are dairy products and dairy alternatives (such as fortified soy milk). You should aim to have at least three serves of these products each day. If you are unable to achieve this, you should consider taking a calcium supplement.

Vitamin D is made in the body when our skin is exposed to sunlight. Following transplant it is unsafe to spend too much time in the sun; therefore you may require a vitamin D supplement.

Food safety

ISSUE 05

After your transplant you are at an increased risk of infection as immunosuppressant medications reduce your immune defences. The food you eat can be a potential source of infection, and as you will be on immunosuppressant medication for the rest of your life, we recommend following these four key steps to improve the safety and hygiene of the foods you eat:

- Keeping a clean kitchen
- Proper food handling
- Proper food storage
- Safe food choices (including eating out)

Please speak to your Dietitian to request a list of the high risk foods we recommend avoiding, together with the safer alternatives.

HIGH RISK CHOICES			
Soft eggs	Raw fish	Soft cheese	Paté
SAFER ALTERNATIVES			
Well cooked eggs	Well cooked meat	Hard cheese	Cooked vegetables

Common signs of food-borne illness include:

- Fever and chills
- Nausea and vomiting
- Headaches
- Diarrhoea
- Muscle and stomach pain

If you suspect you could be suffering from a food-borne illness then contact your GP or transplant nurse immediately.

Remember that every patient's journey is different, as are their nutritional priorities and goals. If you have any questions about your individual nutrition needs, please discuss with your Dietitian.



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

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

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



HLTTV's valued program partners



Heart to Heart House, Barmah Vic
...a great place to relax

For bookings and information

Martina McArdle 0409 957 492 | **Laraine Anderson** (03) 9770 7197 or 0418 599 745

TRANSPLANT 2019 ANNIVERSARIES



HEART

MAY 2019

Karen Murray, 2014
Neal Pearson, 2011
James Sheppard, 2018
Henry Smeets, 1996
Kevin Williams, 2003

JUNE 2019

Marc Bainbridge, 2011
Mark Macleod-Smith, 2015
Maarit Moilanen, 2010
Anne Poole, 2011
Adam Rouse, 2017
Richard Rowlands, 1992
Jim Spooner, 2004
Laszlo Toma, 2006
Larry Virtue, 2014
Janet Wager, 2009

JULY 2019

Petra Brosch, 2018
Russell Freeman, 2005
Eric Holt, 2011
Nichola Mardon, 2015
Bernie Mithen, 2008
Claude Turco, 2007

TRANSPLANT FACT

Australia recorded 129 heart and 221 lung transplants in 2018.

The overall Australian donation rate in 2018 was 22.2 donors per million people (dmpm).



LUNGS

MAY 2019

Colin Dowell, 2016
David Goodluck, 2015
Lynn Pendry, 2017
Sarah Quinn-Paget, 2002
Emma Ross, 2016
Peter Stoate, 2015
Medina Sumovic, 2016

JUNE 2019

Donald Cripps, 2018
Shirley Hodgson, 2008
Barb Maywald, 2006
Vanessa Scott, 1999
Elzbieta Slizankiewicz, 2013

JULY 2019

Lynette Blackshaw, 2018
Carole Bloomer, 2013
Sonia Hapi, 2015
Dawn Honey, 2015
Tricia Martakis, 2011
Irene Perera, 2014
Maggie Verbeek, 2015
Kathryn Wright, 2010
Steve Wright, 2011

TRANSPLANT FACT

Australia currently has four adult lung transplant programs: Brisbane, Sydney, Melbourne and Perth with post-transplant care in Adelaide and Hobart beyond the 3-month mark.



The Alfred Nurses on 3 East, a congaline of smart, professional, intuitive, responsive, caring, beautiful, fun people bringing their special brand of care to the VAD and Transplant patients.



Fun and treats at the recent HLTV BBQ

**Make a secure
donation**



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.**

Simply follow the prompts.

GiveNow.com.au



Our Vision

Our Vision is for a bright and active future for all those involved with or in need of a heart or lung transplant.

We actively encourage organ donation and support The Alfred Hospital Melbourne, the Transplant Team, patients, recipients, their families and carers throughout their journey.

Our Values

HOPE

We provide a sense of confidence, belief and realism throughout the experience.

LEADERSHIP

We lead and promote a focus on caring, advocacy, support and community to those who share in the transplant journey.

TEAMWORK

We believe our success depends on how well we interact and communicate with others. We inform, network, collaborate and partner with all relevant stakeholders. We have a bias towards action.

TRUST

Our integrity is fundamental in all that we do and stand for. We act ethically and honestly at all times. We do what we say.

VITALITY

We approach our task with compassion, understanding, strength and *joie de vivre*.

Biopsy is key

Endomyocardial biopsy (EMB), or cardiac biopsy, is the most effective way to detect transplant rejection following cardiac transplantation.

Acute rejection is common immediately after cardiac transplantation, but the risk of acute rejection diminishes over time and only represents less than 2% of rejections at more than five years.

Significant complications from acute rejection have decreased over time due to advances in immunosuppressive therapy and better surveillance techniques.

Endomyocardial Biopsy

Endomyocardial biopsy (EMB), or cardiac biopsy, is the most effective way to detect transplant rejection following cardiac transplantation. It allows clinicians to optimise immunosuppressive therapy whilst avoiding rejection and minimising long term medical complications from immunosuppressants, such as hyperlipidaemia, diabetes mellitus, kidney dysfunction, hypertension and cancers.

At periodic intervals following heart transplantation, patients undergo EMB of the right lower chamber of the heart via one of the neck veins (usually the right internal jugular). On average, patients are expected to undergo at least 15 EMBs in the first year. After the first year, EMB is done based on clinical requirement only. The normal biopsy schedule in the first year is: weekly in the first 6 weeks, every 2 weeks for the next 6 weeks, once monthly for the next 3 months, then two-monthly for the last 6 months.

The EMB Procedure

An EMB session is usually performed as a day procedure, with the patient awake and able to go home after a short period of monitoring. The patient's neck (usually the right side) is first cleaned

with a sterile solution, with the face and upper body covered with a sterile drape leaving an open surgical field in the middle of the drape for access to the vein.

An ultrasound probe is then used to locate the neck vein (usually internal jugular vein). Local anaesthetic is then used to minimise patient discomfort during the procedure.

A puncture needle is then inserted into the vein, again under ultrasound guidance (Fig 2), a guide wire is inserted, the needle removed, and an 8F sheath inserted. This is commonly named the *Seldinger Technique*. The clinician is then able to measure the central venous pressure which allows guidance on the patient's fluid status (normal value between 2-8).

EMB is performed using an instrument called a biptome (Fig. 1), first created more than 50 years ago.

About 4 or 5 specimens are taken with the grasping end of the biptome during each session. These are usually sent off for histopathology for identification of cellular rejection. An additional stain can also be performed to look for antibody-mediated rejection.

Evaluating biopsy samples

A grading scale for heart transplant biopsy - developed by the International Society of Heart and Lung Transplantation - standardises the

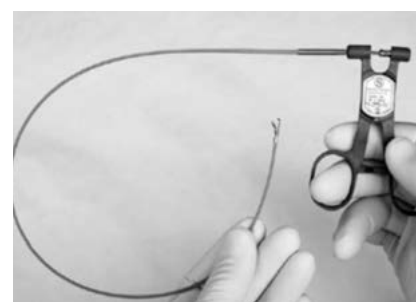


Fig 1 - Novel biptome



Figure 2 - Patient's neck under shroud

description of biopsy specimens under the microscope. In the evaluation of EMB, the higher the grade, the worse the appearance of inflammation within the heart muscle (Table 1). This grading scale, however, does not include antibody-mediated rejection.

The biopsy findings of Grades 0 and 1 do not indicate a need for additional treatment beyond normal baseline immunosuppressive therapy.

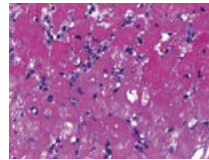
Findings of Grade 2 usually indicate moderate rejection, and patients normally receive short courses of intravenous steroids.

Grade 3 findings usually mandate heavier additional therapy, usually interval intravenous steroid therapy plus an anti-thymocyte globulin (ATG) infusion – a horse, or rabbit-derived antibodies against human T-cells. Regardless of the timing post transplantation, following a Grade 2

ISHLT Standardised Cardiac Biopsy Grading for Acute Cellular Rejection

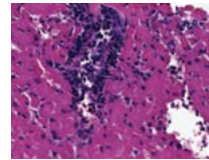
Grade 0R	No rejection
Grade 1R, <i>Mild</i>	Interstitial and/or perivascular infiltrate with up to 1 focus of myocyte damage
Grade 2R, <i>Moderate</i>	2 or more foci of infiltrate with associated myocyte damage
Grade 3R, <i>Severe</i>	Diffuse infiltrate with multifocal myocyte damage +/- oedema +/- haemorrhage +/- vasculitis

Table 1 - ISHLT revised grading for acute cellular rejection



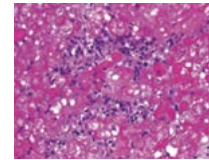
Example of Grade 0R

Scattered isolated inflammatory cell (blue) without clumping together to evidence of muscle damage



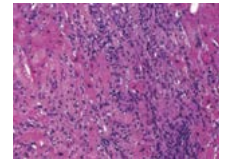
Example of Grade 1R

Compact inflammatory cell aggregate without evidence of muscle damage



Example of Grade 2R

Increased inflammatory cells aggregate with multiple degenerating muscle cells



Example of Grade 3R

Severe rejection with diffuse inflammatory cells and extensive muscle damage

or 3 rejection patients need weekly biopsy until advised otherwise.

As mentioned above, cellular rejection is challenging to diagnose and manage. Signs of cellular rejection usually include increased swelling of the heart muscle (on biopsy, and on imaging such as cardiac MRI and echocardiogram), heart failure or graft dysfunction despite absence of cellular rejection, or persistent cellular rejection despite adequate immunosuppressive treatment.

Since its invention more than 50 years ago, the technique of EMB has been refined such that it now represents

a safe and relatively quick procedure in the hands of a trained operator. Nevertheless it is not without risk. Complications of a cardiac biopsy include infection, pneumothorax (punctured lung), cardiac tamponade (blood accumulating around the heart) and clot formation in the vein that is used for biopsy.

Su Ling Tee MBChB FRACP

Heart Failure and Imaging Fellow

The Alfred Hospital Melbourne

Cardiologist

Victorian Heart and Lung Clinic

**ANYONE
CAN GET THE FLU**



YOU NEVER FORGET THE FLU

betterhealth.vic.gov.au/flu

WHO SHOULD GET THE FLU VACCINE?

Anyone aged six months or older is encouraged to get an annual flu shot.

The flu can have serious and devastating outcomes for vulnerable people with a weakened immune system – especially lung and heart transplant recipients (and their immediate families), young children and the elderly.

That's why the flu vaccination is free for:

- children aged 6 months to under five years of age (Victorian Government funded program)
- pregnant women
- people aged over 65
- Aboriginal and Torres Strait Islander people (6 months and over)
- people with chronic medical conditions.

By getting your flu shot, you're not just protecting yourself, you're also protecting vulnerable people who cannot receive the vaccine themselves such as young babies less than six months old and those who have low immunity.

Some doctors or other immunisation providers may charge a consultation fee. Please check with your local immunisation provider to see whether there are any costs involved.

Use the immunisation service finder at betterhealth.vic.gov.au/flu to see where you can get your free flu shot

Time to remember

The Service of Remembrance is a time to acknowledge donors and their families who make life-saving organ and tissue transplants possible.

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

Let me tell you about this year's Service of Remembrance and the reason why I like to attend.

It gives me a chance to really focus on how lucky I was that a family's kindness gave me my 'second chance'. I have the opportunity to meet wonderful donor families and to catch up with the medical and administrative *DonateLife* staff, and of course chat with other transplant recipients, including heart and lung recipients.

The Service can be very emotional, starting with the words of welcome from Bernie Dwyer from the [Organ and Tissue Authority](#), followed by the



stories from the donor families and the recipients, along with the beautiful music.

Julie Smith, mother of donor Matthew shared her son's story

– Matthew was incredibly giving in life, as he was in death at the age of 35 caused by an asthma attack. Over the last six years, he has continued his legacy with almost 40 people receiving his life-saving and transforming gifts.

Alex Marlow, brother of donor Richard

– Almost 10 years ago, Richard gave the ultimate gift when became an organ and tissue donor following a single car accident when he was in his 30s. Several people received life-altering transplants as a result of Richard and his family.

James Sheppard, heart recipient

– James received a life-saving heart transplant in 2018. He is certainly getting on with his life!



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

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



Contact Belinda on president@hlttv.org.au or 0414 582 945 to discuss how to get involved

Valencia Tadiyono, mother of liver recipient Chloe – *Chloe's life was saved in 2017 when she received a liver transplant at just eight months. From birth she struggled but here she was on the day a bright and happy 2 year old.*

Julie Pavlovic from the Austin Liver Transplant Unit has had the unique opportunity to work on both sides. She shared with us what impact that working in this field has had on her.

Three members from the Royal Melbourne Hospital Choir sang these beautiful songs and it was hard to hold back the tears:

'Little Wonders' by Rob Thomas;
'Somewhere Only We Know' by Keane;
'Time After Time', Cindy Lauper

Following a moment of silence we watched the photographic acknowledgement of the people who donated organs and tissue, and people who have received the gift of donation. For the first time a caption told us who was a recipient rather than wondering who were donors and who were recipients.

Before the Service I began chatting with a donor family sitting behind me and

we talked about why they had come along. The family showed us a photo of their loved one who had passed away from a heart attack in his 20s leaving a son. When his photo came up it meant so much more to me. The family said they hadn't heard from any of the recipients and I know they are hoping to hear from someone.

At the end of the Service we were given the opportunity to write a message to hang on one of the tribute trees. Afternoon tea was then enjoyed by everyone.

Thanks to all those involved through DonateLife in organising the 2019 Remembrance Service.

The Service of Remembrance is held on the last Saturday of May each year.

Gaylynn Pinniger
Heart Recipient 2002



donatelife.gov.au



Protect yourself and your family
Wash your hands regularly



Donate NOW



I / We would like to make a donation to the Heart and Lung Transplant Trust (Victoria) Inc

Name

Address

Postcode

Telephone

Mobile

Email

Donation \$

Donations over \$2 are tax deductible.

Please return this form to:

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



You can also visit <http://www.hlttp.org.au> and look under 'Quick Links' and choose one of the 'Donate Now' links



Pictured: Camille Condon, Louisa Walsh and Matthew Orchard.

Volunteer, advocate, friend

Camille's life is a testament to the difference organ donation can make, and she never stopped spreading that message.

The HLTTV committee and community have been saddened by the recent passing of past committee member and Vice President, Camille Condon.

Camille joined the HLTTV as a volunteer before her transplant and sat on our committee for 5 years as an elected member. She had a dedication to patient advocacy, supporting other transplant recipients, and fundraising.

Camille initially started with the committee after over a year waiting for transplant. She wanted to connect with the post-transplant community and also wanted a distraction from being on the waiting list. In this time she started to apply her signature graphic design style of rainbows, flowers and bright colours to HLTTV promotion work, and I'm sure many of our members would recognise a 'Camille original' BBQ poster or Facebook announcement.

After being with us for a few months we were all delighted when Cam finally got her new lungs after more than 18

months on the waiting list and a few false starts.

Camille went on to become the brains and the power behind many of our most innovative fundraisers, including the *Breathing to a New Beat Technicolour Dream Book*, the *Wallendar*, the *Paint-Along* and the Melbourne Marathon team. She was also one of the voices behind our social media pages, and made networks and friends through [DonateLife](#), [Transplant Australia](#) and beyond. Camille was not only dedicated to the post-transplant community, but was also an active advocate for organ donation promotion, and used her extensive networks and social media presence to spread the word whenever she could.

Cam didn't have the easiest time post-transplant, but has always honoured her donor and donor's family by living well and making the most of every day – even during the most challenging of times. Her life is a testament to the difference organ donation can make, and she never stopped spreading that message.

Camille also made connections with the *Primary Immune Deficiency* research community, and I don't doubt she would have shared her experience generously and gone on to do amazing things in that community as well if she'd had the chance.

Camille was diagnosed with a very rare cancer at the start of this year, and knew that her remaining time was short. Even during this extremely difficult time she was thinking of our community, continuing to encourage those who wanted to show her support to join the organ donor register and donate to HLTTV. She was a great friend to many of our committee and members and is very missed and very loved.

Our hearts go out to all that knew Cam, but especially to her family – including her siblings and her much loved gaggle of nephews – her close friends, and her ever-present dog, Wally. She was an amazing volunteer, advocate and friend.

Vale Camille Condon.

Exercise is for life!

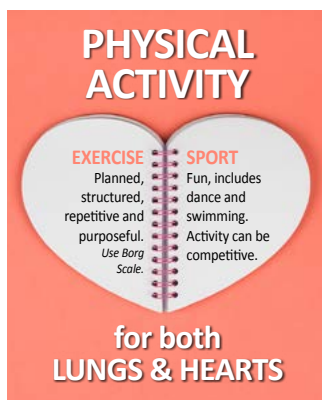


For heart transplant recipients only, remember, do not use formulas involving heart rate to gauge exercise... *use the Borg Scales*

After transplant, you are expected to complete a minimum of 30 minutes of cardiovascular exercise every day.

Daily means EVERY day, not some day

Daily exercise helps strengthen your muscles and bones, and can offset some of the side-effects from your medications. Exercise helps with weight control and managing your blood sugar levels.



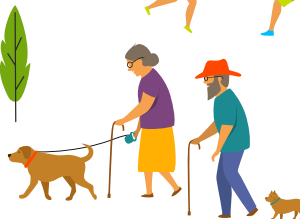
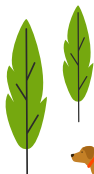
Enjoy the moment

Choose exercise activities that you enjoy and don't forget about playing sport! Exercise with friends or family to keep you motivated.



Live a healthy life

Remember to drink plenty of water, eat fresh, healthy foods, take your medications and exercise daily!



BORG SCALES

SHORTNESS OF BREATH

0	NOTHING AT ALL
0.5	VERY, VERY SLIGHT
1	SLIGHT
2	VERY SLIGHT
3	MODERATE
4	SOMEWHAT SEVERE
5	SEVERE
6	
7	VERY SEVERE
8	
9	VERY, VERY SEVERE
10	MAXIMAL

PERCEIVED EXERTION

6	
7	VERY, VERY LIGHT
8	
9	VERY LIGHT
10	
11	FAIRLY LIGHT
12	
13	SOMEWHAT HARD
14	
15	HARD
16	
17	VERY HARD
18	
19	VERY, VERY HARD
20	



How can I claim PARKING CONCESSION at The Alfred?

Am I eligible? To claim a concession rate for the Patient and Visitor Car Park you must be attending the hospital and be an eligible concession card* holder.

How to claim: Appropriate identification must be produced on each occasion to obtain the reduced parking rate. Before you leave the hospital, show your ticket and concession card at one of the following locations:

- Reception Desk, The Alfred Centre, 7am – 6pm
- Main Reception, Commercial Road entrance, 7am – 6pm
- Car Park Office, Ground floor, Multi-level Car Park, 7am – 6pm

Parking ticket validation is not required on weekends or public holidays as a flat rate applies for all visitors.

Financial hardship consideration: For more information regarding a further concession for 'financial hardship' contact the Manager of Patient & Family Services at The Alfred on (03) 9076 2027. For all other parking enquiries phone (03) 9076 3244.

* For holders of valid Pension Concession Cards, Health Care Cards and Disability Parking Permits. Alfred Health staff, students and contractors are not eligible.

Remember to support our generous sponsors

Aberdeen Abbey Guest House, Geelong

Anonymous Wines

The Ark Clothing Co

Azali – Eastland

Bar 81 – Berwick

Bayview on the Park

Bunnings – Abbotsford

Cadbury

Coomoora Cottage – Daylesford

Discount Chemist – Berwick

Finsbury Green

Handcrafted Flowers

Health Smart Pharmacy Alfred

Heart to Heart Respite House

Kingston Heath Golf Club

Loom Auto Electrical Service

Mancine Professional Products

– Jenny

Melbourne Mustangs

Ice Hockey Club

Mesh Hair Spa Salon

Phillip Island Nature Parks

Piccoli Portraits

Priceline Chemist

Shiel Abbey

St Kilda Football Club

The Grand Hotel Warrandyte

Torquay Rotary

Village Cinemas

Warrandyte Goldfields Bed and Breakfast

Woodlands Golf Club

If your organisation would like to make a financial contribution to the HLTTV please contact:

Treasurer David Pidgeon

treasurer@hlttv.org.au

or 0450 354 905



New "Welcome" framed messages in each of the HLTTV Second Chance Transplant rooms at the Regis Apartments

Get in touch with the Ballarat Support Group

The Ballarat Transplant Recipient Catch-Up Group was formed in 2017. The group provides recipients and their carers the opportunity to obtain information and education from health professionals in a relaxed and informal group environment.

This is the only group of its type within Victoria, and is endorsed by the Heart Lung Transplant Trust of Victoria, affiliated with the Alfred Hospital.

Ballarat is a regional town in Western Victoria, around 120kms from Melbourne's CBD. Members of the group come from all around Ballarat and surrounding areas, as well as from other outer metropolitan centres such as Geelong and Melton.

The idea for the group was driven by recipients themselves, expressing the need for education and support closer to home.

Topics already covered included skin care, medication guidance and nutrition. Local experts volunteer their time to provide the education and advice is always sought from metropolitan transplant services when required.

Education and information is delivered in an informal local setting, easing the travel burden to recipients and their carers.

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

larna.kennedy@bhs.org.au



Ballarat Health Services

DonateLife Week 2019

Sunday, July 28, 2019 to Sunday, August 4, 2019

Led by the [Organ and Tissue Authority](#), [DonateLife week](#) is a key part of the Australian Government's national reform program to increase organ and tissue donation and transplantation outcomes.

Each year, events are held across Australia during **DonateLife week** to encourage all Australians to register their donation decision and to discuss their donation decisions with their loved ones. Think about it yourself, talk to you family and loved ones.

donatelifegov.au



the Circulator editorial team is keen to review books, magazines and articles that may be of interest to the transplant community. We're also keen to promote the work of those who have embraced their second chance at life to explore their creativity or pursue their dreams.

Contact Belinda on president@hlttv.org.au

Items for review can be posted to:

Editorial team c/o PO Box 25036, Melbourne Vic 3004

Your membership counts



Heart and Lung Transplant Trust (Victoria) Inc

Name

Partner's name (if applicable)

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 ☐

I wish to receive my copy of 'the Circulator' by email

☐

Yes

☐

No

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** | **other** | **supporter** (please specify)

Signature

Date

Membership for Pre-transplant members is free. An annual fee of \$15 applies to all other category of member. 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 donations. Donations over \$2 are tax deductible.

Please return this form to:

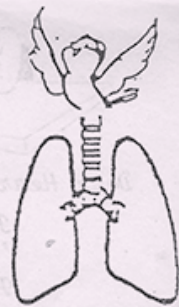
Membership Officer, Heart and Lung Transplant Trust (Victoria) Inc
PO Box 25036
Melbourne 3004 Victoria



Members may also join online and pay membership and donation via direct debit bank transfer. Please visit <http://www.hlppv.org.au> and follow the 'Membership' links.



FLOWING FRESH



HEART & LUNG, ALFRED TRANSPLANTS ASSOCIATION'S NEWSLETTER

L 1 Edition 4

JUNE 1993

EDITOR

Russ (Wes) Wesley
Heart 11, May 89
9 Karana Avenue
GROVEDALE 3216
Ph 052 415541

Greetings - sit back and relax, pour yourself a nice hot cuppa, turn up the dial on your heater and then your ready to enjoy this 'winter' edition of Flowing Fresh.

Read all about it - the very latest stats from our very own Alfred Transplant Unit but remember that every statistic represents on the one hand a person, a Life just like you and on the other hand another Donor and Donor Family that said YES - why not take a sip of that cuppa in your hand and pause a moment to Give Thanks for your Life and Your Donor

Dear Heart deals with a very sensitive issue! Can you smell something just a little bit Fishy

You too can Have a B A L L and Win a Prize

A guest Profile and Thanksgiving Service

Report .. letter to the editor ...

Another New Donor Card / Leaflet

So read, enjoy & contribute

Next Edition is September

So Spring Into Action

and don't forget to wash your cup! *Wes*

WHO AM I?



Personal Profile

FAMILY Wife Maureen, Lisa 24, Shaun 20, Meagan 17, Married 25 years

MUSIC From Classical to Country & West to Jazz (does this depict your lifestyle)

HOBBY Reading Novels of Substance & Playing Golf (substance a ha?)

TU Today Documentaries, Tomorrow Documentaries! (on the Heart?)

FAVORITE PLACE 'Paris' Buildings & History.

PERSONAL WORD I find it a privilege to be a small part of something special - People with Courage.

Editor - Thankyou Geoff Scully, one of three Victorian Transplant CO-ordinators, Geoff is based at Monash Medical Centre but his U I P role takes him to all hospitals with many of Flowing Fresh's readers owing their gratitude for his intervention in their 'Gift of Life'

SERVICE OF THANKSGIVING 1993

A very special time indeed, for about 1,000 people packed into St Francis Church in the City.

3 young children reflected on what their new 'organ' had meant to them - that was very moving, so was the opportunity to light a candle for the 'New Life' and/or to remember the donor - How special and moving was this .. no words can explain.

Advance notice of this Annual Service will be in the March edition of Flowing Fresh 1994 So you can play your part in a very Special Day - Moment. *Rd*



Dear Heart

93

Dear Heart,

I don't quite know how to ask this but - but do you think that 'knowing or knowing of your Donor' is a good thing or not such a good thing?

RL

Well RL, I was hoping for an easy question! But all questions to do with Transplantation are equally important, often complex and always sensitive. RL you no doubt are a sensitive person to be thinking of this question and you are not alone. Many a recipient and Donor family member have - had a sleepless night, thinking about this very question or is it really, like you, they are thinking about People - The Giver and Receiver.

As I'm sure you have found out - some people will answer your question with a strong NO! They say; You may not like the Donor or the Donor's Family and they may not like you ... what then? You can't give the Transplanted Organ back! They have a point there.

Others will respond to your question with a strong YES! They claim it would help in a persons recovery, in their adjustment, in their quest for identity and the Donor's family will have a real life to give thanks for and not just a mystery recipient. This is a positive attitude and for some the opportunity to thank the Donor family in a personal way may have real benefits.

As for me - I'm a softy at heart and so I don't go for a strong No and I don't go for a strong Yes. I want to stay with a 'sense of mystery'. You see, on the one hand you didn't ask to be sick or struck down with a virus nor did the donor ask to be struck down by an accident and sickness. Such is a mystery for both - the timing is a mystery too - can anyone explain this coming together? So I kind of feel that to bring together in a human controlled sense the donor's family and the recipient while it is not wrong, it kind of interferes with that 'mystery' - I feel more comfortable with the mystery and accepting such that in my limited humanity, trying to make all the loose ends tie together and fit neatly into a Transplantation Box - if you know what I mean

Dear Heart

SALMON PATTIES (GRANNY DAVIS)

1 425g can red salmon (N.B.)
1 onion finely grated
2 eggs
2 tablespoons approximately
sieved plain flour
1 dessertspoon chopped parsley
Pinch pepper
N.B. Use only the best red salmon

- Remove black skin and large bones salmon, mash with fork
- Add eggs one at a time to mashed salmon
- Add grated onion, parsley, pepper and lastly, sieved flour to salmon mixture
- Mixture should be moist
- Spoon into hot oil
- If pieces of mixture break off you need to add a little extra flour to bind - too much flour spoils the texture and flavour

Fish



This recipe comes from the book - **CARDIAC CUISINE**, published by the St Vincent's hospital (sydney) Transplant Association, the cost is \$13.95 incl postage - 126 pages of fantastic recipes ... phone 02 361 7502 or write to; P.O. Box 44, Condell Park, NSW 2200.

CARDIAC CUISINE!!!

THE

THE ALFRED HOSPITAL
HEART & LUNG
TRANSPLANT FAMILY FUND

PAGE



14/3/93 A Great Time and Great Feed
was had by all at the Biopsy Bash



The Alfred Hospital
Heart & Lung Transplant Family Fund
Annual Fundraising Raffle 1993

Prize	Retail Value
1st	\$500.00
2nd	\$300.00
3rd	\$200.00
4th	\$200.00
5th	\$200.00
6th	\$200.00
7th	\$170.00
8th	\$150.00
9th	\$100.00
10th	\$80.00
11th	\$80.00
12th	\$50.00
13th	\$50.00

\$500.00 gift voucher courtesy of Coles Myer Ltd
 Chef Microwave Oven (MX135) courtesy of Chef Australia Pty Ltd
 Rinnal B.B.Q. courtesy of Rinnal Australia Ltd
 \$200.00 shopping voucher courtesy of Plan Central Shopping Centre
 Jarvis-Walker fishing rod courtesy of Barry Hayward (Transplant patient)
 Ralindance 'one step' water filter courtesy of Allergy Aid, Prahran & Reindance
 Selection of C.D.'s and cassettes courtesy of Warner Music Australia
 Haircare vouchers courtesy of Avner's Hair Salon, Prahran
 GTX 2 products courtesy of Castrol (Australia) Pty Ltd
 Dinner for two courtesy of Balavia Scherzade of Armadale
 6 blank video cassettes courtesy of Heart & Lung Transplant Fund Committee
 Swiss army knife courtesy of City Centre Disposals
 Whitney Green handbag courtesy of Peter Beardsley (Director)

Consent of the Raffles and Bingo Permit Board C47293 granted 28/4/93 given for sale of tickets in Victoria from 9/5/93 to 18/9/93. To be drawn 18th Sept. 1993 at SAN REMO BALLROOM, NORTH CARLTON at 10 p.m.
 Results published in 'The Herald-Sun' on 25/9/93. Winners notified. Not transferable.
 Secretary: V. Morgan Treasurer: A. Ashkenazi

The Alfred Hospital
Heart & Lung Transplant
Annual Fundraising
Raffle 1993

Name: Recipient

Address: Yes - Rush
me back
to sell - 1
want to win
such Great
Prizes

Phone: 826 6969

\$1 per ticket 20,000 tickets in total

Sample Only

Donated & Printed by The Graphic Print Centre, The Total Copy Centre and Frances O'Hole (Transplant Patient) & Family

Phone Avner on 03 826 6969

For Your Raffle Book and Tickets for the B.P.

ALL PROCEEDS GO TO:
THE ALFRED HOSPITAL
HEART & LUNG
TRANSPLANT FAMILY FUND



San Remo Ballroom
365 NICHOLSON STREET
NORTH CARLTON
SATURDAY SEPTEMBER 18, 1993
7.00pm for 7.30pm
4 COURSE MEAL
BEER, WINE, CHAMPAGNE,
SOFT DRINKS
\$ 50 PER HEAD
LOTS OF PRIZES!!!!
SPECIAL GUEST ARTIST

FOR BOOKINGS PHONE: 826 6969
OR
SEND TO:
1-4 9 STRUAN STREET, TOORAK 3142

NAME:
ADDRESS:
NO. OF TICKETS: ENCL:
Please make cheques payable to
The Alfred Hospital Heart & Lung
Transplant Family Fund

EARLYBIRD SPECIAL!
BEFORE JULY 18 40c
PAY ONLY \$40 PER HEAD!

NEWS RELEASE

The latest statistics from the Alfred
as at June 7th 1993

Total Heart Transplants	157
Total Heart/Lung "	33
Total Single Lung "	20
Total Double Lung Sequential	9

Donors! People!
219
Lives!
Gift of Life!



LETTER TO THE EDITOR

After reading Mrs. W.'s question to Dear Heart (March Edition), I was reminded of my Own Why Me? thoughts and feelings now that I am waiting for another Heart / Lung Transplant or this time just Lung. I have learnt to look at things positively now and so I say ... Why Not Me? I ofcourse have a combination of feelings and thoughts, such as Humility - feeling sometimes unworthy of such a Gift. Gratitude - toward the Donor and even the opportunity to have in my case another Transplant, as well as to be alive today when medically such is possible.

* And for the wonderful doctors and staff of the Alfred Transplant Unit.

I really believe God has a plan for each of us, while my life has been at times difficult, I can look back and see a Plan, still yet unfinished! - so positive feelings, thoughts and faith enable me to live the wonders of a New Day.

(P.S. Cut short due to space, Editor.)

Gaye Scott H/L 3

Donor Card

NEW

DECIDE
TO BE AN
ORGAN DONOR

TELL
YOUR FAMILY

☒ GIVE & LET LIVE

Decide to be an organ donor and tell your family

I request that after my death (tick applicable box):

My ☐ kidneys ☐ heart ☐ liver ☐ lungs ☐ pancreas ☐ eyes
be used for transplantation; or

☐ Any part of my body be used for treatment of others.

Signature: _____

Date: _____

Full Name (Block Capitals): _____

In the event of my death, please contact:

Name: _____

Address: _____

Telephone: _____

For Your Supply Call 018 018 995 / Card and New Leaflet it's GOOD!

THE
LAST
WORD

Well Done Gaye and you have all our support as all people on the wait list need. Also - note, the next edition of Flowing Fresh is September, so please send me your contribution, big or small by the end of August and Don't FORGET ... The Back Page LOOK for your \$10 dollar discount and I want every reader to ring for some raffle books. New Subscriptions to F & F welcome send \$2.25 stamps

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Telephone: _____

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TELL
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You're invited



to the

HLTTV

25th Anniversary Celebration Dinner

Saturday 31 August 2019

**Bayview on the Park
52 Queens Road, Melbourne**

6.30pm start

If you have any specific dietary requirements please call
Martina 0409 957 492 or Maarit 0400 190 356



**HEART AND LUNG
TRANSPLANT TRUST
VICTORIA**



**Bring your family, friends and colleagues and enjoy a fabulous
night of entertainment, dancing, auctions and games!**



When you're good at something
you'll tell everyone.

**When you're great at something
they'll tell you.**

You're welcome.



Finsbury
Green

finsbury.com.au