Third Quarter | 2018 | Issue No. 93

the circulater 2018 Issue No. 93 Circulator Heart and Lung Transplant Trust

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findfulness interview with Dr Grant Blashki

SERVICE OF REMEMBRANCE



Heart and Lung Transplant Trust (Victoria) Inc A0037327C/ABN 68 585 966 022 Third Quarter | 2018 | Issue No. 93 www.hlttv.org.au

Editors Report

Hey everybody,

Welcome to the third quarterly edition of the Circulator. It is crazy to think that we are already at this point in the year, when It feels like the Easter BBQ was yesterday! But do not worry there is plenty more to look forward to at HLTTV - with the Spring Gala Ball and Christmas BBQ just around the corner!

After reading this edition get ready to feel inspired! The stories that have been shared with us from both members and supporters are truly amazing – with incredible examples of courage and generosity.

Peter Ketelaar tells his story of struggling with Tetralogy of Fallot for 65 vears, and the life changing experience of receiving a new heart, whilst the Patching/Thompson families open up about their difficult journey of having a father with prostate cancer and a brother with Hypoplastic Left Heart syndrome - and how this motivated them to 'shave for a cure'.

We even have our own mini version of a fairy tale – with the story of Kirsten and Les's 270 'magical pumpkins'! All of which were grown in their back garden and used to raised funds that have now been donated to HLTTV.

I was also lucky enough to get time with the Lead Clinical Advisor of Beyond Blue – Associate Professor Grant Blashki, who discusses some helpful mindfulness strategies, and how to implement them in dealing with the worry and stress often associated with chronic disease.

Which brings me to my last point – we thought it would be a good idea to start asking a general question to our readers each issue about topics of conversation that would be relevant to members and their families. All responses can be emailed to circulator@hlttv.org.au

Question: Are there any health apps, websites or forums that YOU find useful for helping with medical issues or queries?

Hope you enjoy this issue,

Ariella – Circulator Editor.

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Presidents Message

Hello everyone!

I'm keeping it short and sweet today because as I write this I'm about to head off on a bit of a Winter break to warmer climates and I have a few jobs to do before I run away. I hope that you all have similar plans for a little escape and making sure you're finding some fun (with or without sun) in the depths of winter.

My message today is mostly about all the great things we have coming up that you can read about in this edition of The Circulator! We are trying hard to offer our members, supporters and friends some extra special events, and there really is something for everyone coming up.

On the 31st of July we had our first ever movie night. It was a great turn out with a great mixture of members, their families and other supporters. The popcorn was flowing and the laughs never-ending – the NZ comedy 'The Breaker Uppers' was a real hit! We hope to do this again some Finally, on the 25th November we're having our annual Christmas BBQ in Fawkner Park. Another free event for all our community - come along, bring a friend, enjoy a snag.

Plus – I know that these events are all Melbourne-

centric, and we have members from all over Australia. To fill this gap we have just developed a project funding proposal process. If you have an idea which supports the transplant

community in your local area, all you need to do is head to this webpage: , complete the form, and send it in to the committee for consideration. We'd love to support your ideas for helping our community!

Phew! I'm tired just thinking about all these events. Hope to see each and everyone one of you soon – whether it's taking in our great city with thousands of others at the Melbourne Marathon Festival, or across the dancefloor at our Spring Fling!

time soon as it was great way to catch up with everyone.

On the 1st of September we're having another Gala Evening fundraiser. This time the theme is Spring Fling, so dress in your brightest spring colours and let's welcome back the sun together. Tickets are \$75/head for a three course meal, and this is our biggest fundraiser of the year, so we hope to see you, and a table of your nearest and dearest come and be a part of the night! We had a BALL in 2017, so join us for 2018.

Then, on October 14th the HLTTV team is taking part in the Melbourne Marathon Festival. So far we have runners and walkers in the 3km, 5.7km and 10km events. We'd love for you to join us as well, and our biggest crew are the 3k walkers, so don't feel you need to be able to run to participate. If you'd like to know how to join, contact Camille –

vicepresident@hlttv.org.au

or check out the event on the Facebook page.

Give now

Donations to the Heart and Lung Transplant Trust (Victoria) are fully tax deductable and easy to do using <u>www.givenow.com.au</u> Simply visit **hp:**/ <u>givenow.com.au/hlttv</u> and follow the prompts.



HLTTVs valued program partner

A great place to relax

Heart to Heart House Barmah Vic

Bookings & Information

Martina Appelman Mobile 0409 957 492

Laraine Anderson Tel 03 9770 7197 Mobile 0418 599 745



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 discount rates.

Since May 2012, HLTTV have been thrilled to partner with the Park Regis Griffin Suites to provide affordable, accessible and practical accommodation for regional transplant recipients.

Park Regis Griffin Suites have partnered with our Second Chance Accommodation Program to provide eight, 1 bedroom apartments for the use of transplant recipients. Situated between Melbournes city centre and St Kilda Beach, the Park Regis Griffin Suites features include a range of different accommodation options, an onsite cafe/bar and a tram practically at the front door. Park Regis Griffin Suites Phone | (03) 8530 1800 Location | 604 St Kilda Road, Melbourne Email | griffen@parkregishotels. com

Web | <u>www.</u> parkregisgriffinsuites.com.au



Leisureinn 🌭 👾 PARK REGIS





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 the 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.

The Circulator editorial team is keen to review books, magazines and articles that may be of interest to the transplant community. Were also keen to promote the work of those who have embraced their second chance at life to explore their creativity or pursue their dreams. If youve got a story youd like to share, please send directly to our editor for consideration.

Contact Ariella by email | <u>circulator@hlttv.org.au</u> Hard copy items can be posted | Editorial team C/O PO Box 25036, Melbourne, Vic, 3004.

Ballarat Support Group

The Ballarat Transplant Support Group runs regularly throughout the year and is always keen for new members!

If you are a transplant recipient or carer, live in or around Ballarat, and are interested in being part of the group, please contact Larna Kennedy, Donation Nurse Specialist on 0411 323 006 or <u>larna.kennedy@bhs.org.au</u> for upcoming meeting dates and locations. Any questions or concerns they may have around the trans¬plant process, and to provide moral support by sharing your own experiences.

A New Heart *A New* Life

My name is Peter Ketelaar and I am 65 years old and I suffered from chronic heart disease.

I was born with 'Tetralogy of Fallot', a rare heart condition where there are four defects that affect the heart's function. Unfortunately, I was considered a 'blue baby', meaning I was not strong enough to be operated on until I was nine.

Throughout my teenage years and early twenties, although restricted from doing many things like sports or other physical activities, I tried to live my life as normally as possible. But as I entered my late twenties I had to have a pacemaker inserted in order to regulate the irregular beating of my heart.

Then in my thirties and forties my heart muscle deteriorated, resulting in two more pace-maker replacements. As the condition got worse, my heart could not maintain an efficient blood flow, leading to decreased oxygen intake and difficulty breathing. My heart rate became irregular again, and would at times stop for a few beats. This induced dizziness to the point of fainting. A defibrillator was fitted and

In January 2018 I happened to be in hospital when a cardiac nurse told me a donor heart had been found. The shock and elation I felt was indescribable. I rang my daughter who was also stunned. Within hours I was in the operating theatre. The reality had started to set in. I was getting a new heart. Emotions became very mixed. The extreme happiness coincided with extreme sadness, someone had to pass away for me to live.

To receive the gift of life is unfathomable. There are no words that can express the feelings of appreciation a recipient has for their donor,



and the donor's family. Life has completely changed, and I can do so much now, all because of them.

Like being a baton bearer for the Commonwealth Games Torch Relay. A few weeks after my operation I was nominated by my daughter, and I was lucky to be selected. This gave me a goal to hang onto during my recovery. I felt so proud that day. My donor helped me hold



that baton high, and we walked the relay together.

There are many people who made this all possible and I thank you. A very special thank you must go to The Alfred Hospital Transplant Team, surgeons, nurses, doctors, physics and all the staff. Such an exceptional team of miracle workers.

Thank you.

saved my life on various occasions although it's kick is not a pleasant experience.

In my fifties and early sixties, I became weaker. I eventually had to stop work and seemed to spend more time in hospital than at home. Medications no longer worked and I was told that I would not last much longer. In October 2017, I was put on the heart transplant list.

From that moment my life changed. The wait, the not knowing if, or when, it would happen was an ordeal of its own. I had tremendous support from family and friends, particularly from my daughter Ebony. She moved down from Queensland to be my carer, and without her help, organisation, and love life would have been very difficult.



Please Give Today!

Donations to the Heart and Lung Transplant Trust (Victoria) are fully tax deductable and easy to do using <u>www.givenow.com.au</u> Simply visit **hp:**/ <u>givenow.com.au/hlttv</u> and follow the prompts.





By Ariella Heffernan-Marks

On Sunday the 29th April 2018 the Patching/Thompson families shaved their heads and raised over \$15,000, which they then chose to donate to 'Prostate Cancer Australia' and our very own 'Heart and Lung Transplant Trust (Victoria)'.

This amazing cause was the result of not only generous spirit, but a desire to create awareness, support further research in the early detection of prostate cancer, and to prompt people to discuss organ donation with their families.

But what inspired such an amazing idea..? We were fortunate enough to have the Patching/Thompson families share their personal experience with both cancer and congenital heart disease – this leading them to 'Shave for a Cure'.

"Three years ago we received the heart breaking news that our Dad (Warren) had Prostate Cancer, that has since metastasized. He has gone through many treatments including surgery, radiation, hormone therapy and chemotherapy. He has done it all with an unwavering positive attitude and continued to be an amazing Dad and husband. We made a pact that if Dad lost his hair during Chemo, we'd all shave ours."

"Also, our brother Stephen was born with a congenital heart condition called 'Hypoplastic left Heart Syndrome'. A condition few babies survived in the early 90's. He has gone through countless procedures and operations, including open heart surgery at 5 days old, 7 months and 8 years old. Stephen has always faced every challenge head on and with a big smile on his face. About 12 months ago we received the shocking news that Stephen was in chronic heart failure. He deteriorated quickly and the only option was a heart transplant. Luckily a new heart arrived just in time for Stephen in December last year. There were unforeseen complications during surgery, which is making it a long road to recovery, but in true Stephen style, he's taking it all in his stride and doing fantastic."

"These two men have been through so much but still have such an amazing spirit".

Despite such difficult circumstances, the Patching/Thompson families have taken the opportunity to make the most of a tough situation. They have used it to help others, and to make difference in other people's lives. It is truly admirable and we thank them so much for their incredible donation.

If you would like further information about either charity, please click on the links below.

http://www.prostate.org.au http://www.hlttv.org.au





Photographs: White Vine Photography.

What EXACTLY IS IT AND HOW CAN IT APPLY TO YOU?

There is no doubt that 'mindfulness' is a trending term at the moment, but with that comes a lot of ambiguity about what it actually involves, and how to apply it in a situation that is not necessarily typical to conventional society. Take for example; recovering from a transplant or supporting someone as they go through one. So, I have decided to speak to an expert – Associate Professor Grant Blashki - the Lead Clinical Advisor for Beyond Blue – a foundation working to address issues associated with depression, suicide, anxiety disorders and other related mental disorders

1. What is 'mindfulness'?

Some essential features of mindfulness are the practice of being in the present moment, knowing where your mind's attention is, and learning to keep your attention on where you want it to be. It is based on ancient contemplative practices, especially Eastern philosophies, and often encompasses a broader philosophy of how one perceives the world. Although closely related to meditation it doesn't actually have to involve any particular spiritual practice.

2. How do I practice 'mindfulness'?

A central aspect of mindfulness is the meditation exercises, and there are lots of ways to get instruction on how to do these. You might consider joining a mindfulness class, or even just downloading one of the excellent mindfulness apps for your phone such as *Smiling Mind* or *Headspace* to get started.

3. What are the benefits of using mindfulness psychologically and physically? Is there any research that shows its benefits?

There is much scientific evidence for the benefits of mindfulness including improvements in mental health, managing pain, better sleep, and even metabolic benefits for reducing heart disease. There is also evidence that it can be a helpful approach for people who are coping with serious illness or chronic health issues.

4. What are its benefits specifically for 'recovery', or dealing with a significantly life impacting circumstance such as chronic disease? For people who are coping with chronic disease, the associated worry and stress can exacerbate pain and other symptoms. Developing some skills in mindfulness exercises can be a great way to calm the mind, and to take some time out from the worry and stress. Often our minds get caught up thinking about the past or worrying about the future. Mindfulness helps people to keep their thoughts in the present moment and to stop focusing on negative thoughts. 5. Where do I go to learn more about 'mindfulness'? Is there anywhere I can go to practice it?

There are many mindfulness practitioners, who can provide group or individual instruction on mindfulness. When finding a teacher, it is worth asking who they trained with, their approach and whether they themselves are practicing mindfulness. There is also a lot of good information about mindfulness which is free on the internet such as this link to this excellent book chapter by one of the international leaders in the field Australian A/Professor Craig Hassed.

(http://www.futureleaders.com.a u/book_chapters/pdf/LifeSurfing LifeDancing/Craig-Hassed.pdf)

Thanks so much Dr Blashki for your time – I am sure this will help many of our members develop strategies for practicing their own 'mindfulness' in difficult times, but also in day-today life.

Readers if you visit this link you can find a useful mediation practice uploaded by Dr Blashki on his website Family Doctor Expert -

http://www.familydoctor.expert/m editation-exercise



Dr Grant Blashki



By Kirsten Larsen

It all started when we grew a 21kg pumpkin in 2017, and I saved the seeds. Les (my partner) suggested that it would be a fun idea to sow the seeds along the fence in the paddock behind the retirement village that we live in

So in early spring 2018 we walked along the fence, Les drilled about 80 holes, whilst I walked behind him filling the holes with seed raising soil, seeds

and soil again.

Thinking we would be lucky to see any grow due to the poor soil which was mostly clay and rocks. We were pleasantly surprised when all of sudden they started to grow, not just one or two, but hundreds along the fence line.

In the beginning I started to pollinate and water them on my own, but soon nature took over.

The bees were buzzing and the rain kept coming. Soon we had about 270 pumpkins...but



what were we to do with them?

As we live in a retirement village, we got the idea we could sell them for a gold coin donation for the Transplant Foundation, and everyone agreed it was a great idea.

Thanks to our hard work Les and I grew 270 pumpkins, which come to a total weight of 650kg – which we are proud to say raised \$317 which we are donating to HLTTV.

One of the ladies at our retirement village wrote this lovely poem about the pumpkins.

Kirsten's Pumpkins

One day in early summer She asked her friend the plumber To drill some holes so she could plant some seeds She chose the hardy Pumpkins That's loved by country bumpkins And she know they needed sunshine, soil and Feed She watered and adored them She asked the lord to bless them And woe and behold the pumpkins did Appear They grew so fast and multiplied

And now she sits and wonders why She now has them coming out her ears! By Rosie



HLTTV is entering a team in the Melbourne Marathon Festival once again this year, and we would love for everyone to join us!

It's a great day out and helps to illustrate the importance of organ and tissue donation – but the best thing is that you get to walk or run your finishing lap on the MCG!

This year the event is being held on Sunday October 14th.

There are many distances to participate in: 3km walk, 5km run, 10km run, Half marathon, Full Marathon

When registering online: At the SELECT TEAM question, choose HLTTV - Heart and Lung Transplant Trust Vic - the password is HLTTV At the fundraising question, choose - ANOTHER CHARITY NOT LISTED HERE

We have our own team fundraising page, so you can direct anyone here who would like to make a donation <u>https://run.gofundraise.com.au/page/HLTTVHLTTV</u>



Transplant anniversaries – July 2018

August

- Heart
- Geraldine Ashby, 1997
- Domenico de Maria, 2014
- Neville Eyre, 2002
- Darren Moyle, 2010
- Thomas O'Driscoll, 2012
- Demir Terziu, 2008
- Dean Thomson, 20009

Lung/s

- Nicole Barnes, 2017
- Stephen Kinson, 2012
- Phillip Laffan, 2015
- John Mills. 2008
- Sivaraman Sivapiragasam, 2011

Heart and Lungs

September Heart

- Colin Goodman, 2016
- Lloyd Honeycombe, 2000
- Monty Kleiman, 1993
- Greg Maroney, 2014
- John McLean, 1991
- Sammi Tabone, 2009
- •
- Lung/s
- Shirley Aisbett, 2008
- Martina McArdle, 2009
- Rebecca Berry, 2012
- Gillian Fleming, 2012
- Angus Harrison, 2015
- Gloria Lancione, 2015
- Flynn O'Malley, 2015
- Hassell Rutland, 2009
- Daryl Walker, 2016

- Louisa Walsh, 2010
 Heart and Lungs
 NA
- October

Heart

- John Campbell, 2008
- Phillip Felman, 2005
- David Finlayson, 2015
- Robin Oliver, 2000
- Jeffrey Priest 2008
- Libero Viola, 1992
- Janet Williamson, 2009
- •
- Lung/s
- Kristan Braun, 2015
- James Carroll, 2017
- Jane Fletcher, 1993
- Sharon Golden, 2017
- Carol Huxley, 2012
- Janet Johnson, 2011
- Samuel McKirdy, 2016
- Agnes Russell, 2014
- Valerie Shentzer, 2011
- Andrew Weybury, 2015
- •
- Heart and Lungs
- Claire Stubber, 1996

Donation envelopes

Do you have an event coming up and would like to support the HLTTV? We have branded donation envelopes which were happy to send out to you for use at events where your guests may like to make a donation. If you need some donation en¬velopes for an upcoming event, please contact Louisa <u>President@hlttv.org.au</u> and we can post them out or drop them off to you or a venue at no cost.

"Make sure you book your tickets to the Spring Gala!"

If you have any contacts for goods and/or services for donations for Spring Gala auction items - big or small, let us know. If you need a letter of request or pick up of items or have any queries please contact:

Martina McArdle 0409 957 492 or martina@hlttv.org.au

or Maarit 0400 190 356 or <u>maarit@hlttv.org.au</u> All support appreciated"

ſ	Donate now
	I/We would like to make a donation to the Heart and Lung Transplant Trust (Victoria) Inc.
	Name:
	Address:
	Postcode:
	Donation: \$
	(Donations over \$2.00 are tax deductible)
	Please send to: Treasurer Heart & Lung Transplant Trust (Victoria) Inc
	PO Box 25036, Melbourne, Vic, 3004
	Please visit http://www.hlttv.org.au and look under Quick Links and choose one of the Donate Now links

Become a member now

Heart and Lur	ng Transplant Trust (Victoria) Inc.	Membership Form
Name:		
Partner's name (if applicab	ile):	
Address:	Destas das	
Talaabaaaa	Postcode:	
Telephone: Email address:	Mobile:	
Email address.	Date of birth:	
New member	I wish to become a member of the Trust	
OR		
Existing member	I wish to renew my membership	
I wish to receive my copy o	f 'The Circulator' by aih Yes N	lo
	e information regarding Transplant Type, Operation, M anniversaries if you consent below.)	onth and Year – this allows
Lung/s	Month [] Year []	
Heart Heart & Lung	Month [] Year [] Month [] Year [] Month [] Year []	
Other (please specify)	Month [] Year []	
Are you happy for this in	formation to be included in 'The Circulator' newsle	etter 'Transplant Anniversa
each year? Yes □	No 🗆	
OR		
Pre-transplant (Waiting list)	
OR Carer/other/supporter (plea	ase specify)	
Signature:	Date:	
A membership reminder w	plant members is free. An annual fee of \$15 applies to ill be included with the Winter edition of The Circulator t of a membership invoisæppreciated and we are grate deductible.	r each year.
Please return this form to: Membership Officer, Hea PO Box 25036 Melbourne Victoria 3004	rt and Lung Transplant Trust (Victoria) Inc.	
	line and pay membership and donation via direct bank v.org.au/ and follow the 'Membership' links.	transfer.



