



the Circulator

Heart and Lung Transplant Trust (Victoria) Inc A0037327C/ABN 68 585 966 022

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Giving Thanks for Life



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President's Message

Happy winter! We hope you're staying snug and warm with the cold weather and rain, and that you're noticing the days getting longer now we've passed the solstice.

Work at the HLTTV just keeps rolling along. Our Patient Support Officer Carla writes in this edition of The Circulator about the importance of support post-transplant, and how she is looking to formalise some of our peer support arrangements to better meet the needs of people throughout the transplant journey. If you are interested in learning more, want to seek help, or want to share your experience, contact Carla via patientsupport@hlttv.org.au.

The HLTTV is entering a team again the Melbourne Marathon. The event offers 3km, 5km, 10km, half and full marathon event categories. This year we are focusing on getting a big crew together for the 3km walk event, but if you're interested in another category, you are more than welcome to represent the HLTTV when you run! It's both a great fundraiser for us, and a chance to raise awareness about organ and tissue donation, and transplant. We'd love you to join our team – check out the instructions for registering in this edition.

We're proud to welcome three new life members to our membership ranks – Jon Rolfe, Gerry Hanily and Martina McArdle. Jon, Gerry and Martina are being recognised for their efforts across two Tour de Transplants, raising well over \$400,000 for the Second

Chance Accommodation Program. [au](#) They are three very deserving new life members.

Speaking of membership, it's that time of the year again! The HLTTV membership runs with the financial year, and all memberships are now due. Don't forget to renew so you can keep up with all the happenings and events of the HLTTV.

Finally, we are going to be running a social night in the coming months. More information will follow on our Facebook page, email and through notices at the clinics. We'd love to see you there!

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The 2016 Melbourne Marathon

This year the Heart and Lung Transplant Trust is once again entering a team in the Melbourne Marathon.

The event is taking place on Sunday 16 October and there are five distances to choose from:

The Marathon	42.195 kms
Half Marathon	21.2 kms
Run	10 kms
Run	5 kms
Walk	3 kms

Last year we had a team of 15 representing the HLTTV, and this year we'd love to do even better!

We're going to focus on the 3km walk event to make it as accessible for as many people as possible. It's a great chance for some FUN fundraising while promoting the amazing success of organ and tissue donation.

If you'd like to join in the fun this year, please email Camille – vicepresident@hlttv.org.au for all the details

A note from the editor

Hello readers,

We have a huge edition for you this quarter. This issue is concentrated on a very important theme, that of DonatLife and their campaign to get people to sign up to the organ donor registry.

As always, throughout these pages there is evidence of the difference that organ donation makes in people's lives. It can be seen in the article about David Floyd and Rebecca Berry, two people who have experienced tremendous changes in their lives because of organ donation. It is thanks to anonymous donor that Rebecca Berry has been able to ride

in two Tour de Transplants and that her fiancé David has had the pleasure of participating with her in this year's Tour.

Gaylynn Pinniger writes of an opportunity to give communal thanks for organ donation, the Service of Remembrance.

Gary Quick, whose story appears in these pages, was keen to emphasise the benefit he has gained as a result of organ donation, he penned his story on the occasion of his seventeenth transplant anniversary. His story highlights the fact that a decision made based on a hypothetical situation can lead to a very real life-changing and life-saving event.

The HLTTV is running it's own campaign for DonatLife week, asking members to publicise the amount of time they or their loved one waited for transplant, as a way of highlighting the need for donors. You can see some of those pictures on the back page of this edition.

Our next committee meeting is on the 9th of August and all are welcome to attend.

Happy Reading!

Editor for Quarter 3:
Claire Stubber

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



A great place to relax

Heart to Heart House Barmah Vic

Bookings & Information

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HLTTV's valued program partner

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 six, 1 bedroom apartments for the use of transplantation [recipients](#). [Situated](#) between Melbourne's 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 | griffin@parkregishotels.com
Web | www.parkregisgriffinsuites.com.au

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.



17 Years for Gary Quick

This story was written by Gary Quick on the occasion of his 17th double lung transplant anniversary, Gary's transplant, for Cystic Fibrosis, occurred on the 28th of January 1999

It was first posted on Facebook and so has been edited slightly to reflect this but otherwise appears as written on the day. It is an example of how one person has chosen to raise awareness of the importance of organ donation. It is personal stories like the one below that highlight the difference one decision can make to an individual's life.

In keeping with our DonateLife focused issue Gary has a message for those who have not yet made thought of, or made known, their decision about organ donation.

Hi All,
Today, being the 28th January, is a very significant date for me. So significant that it's prompted me to write another 'selfie' story to share publicly. I know a lot of other people have a similar significant date that is just as important to them, including quite a few of my friends on Facebook, BUT there needs to be more of us so please read on. Warning - this story could get long, but I have something to say and I have a favour to ask everybody who gets to read this. Firstly, I shared this on Facebook as most people on my Facebook page know me personally and only a small percentage of my Facebook friends have known me for at least 20 years. Most of those who have known me for 20 years or more know a lot about my medical history. Those who have known me for

a much shorter period of time won't know my medical history, and nor will those reading this in *the Circulator*, therefore I will now give a brief description and will hopefully enlighten a few people about the importance of how you can help with something...

17 years ago today, both my life and lifestyle were changed incredibly, due to the generosity of an anonymous family. I was



now subjected to about 25 new 'friends' who were a new part of daily life - helping to give me new found energy, strength and motivation. One of these friends in particular - 'Prednisolone' - has now decided to wear me out to the point of me having to seek out 3 more new friends - 'Endone', 'Panadol Osteo' and 'Walking Stick', which are now making life more of a challenge. BUT seventeen January 28s are a lot to celebrate considering the following circumstances...
On the 28th January 1999 I was given the gift of both extended life and MUCH better QUALITY of life.

The reason: Double Lung Transplant.

The absolute best friend: Donor Family.

My donor family is the reason for making my story from January 1999 to this day possible.

But first, before I ask the favour, a



bit more about the way my donor family, medical staff and nursing staff have helped shape my new chance at life...

Back in the mid 90s I was forced to leave daytime work and forced to stop playing in bands, due to increased ill health and extended plus more frequent hospital admissions due to being born with a terminal illness (Cystic Fibrosis). By 1998 I was pretty much 'stuffed' and spent about 5 months of the year in hospital with admissions ranging from 3 to 5 weeks at a time. Being prepared for my final breath of life within the next 2 years, along came the special date in Jan 1999...

So after rehab and acquiring plenty of new chemical friends to digest I have to say that the next 5 years of my life were the most healthy I had ever experienced and could ever have imagined possible. 5 years: That probably doesn't sound like much to a lot of people but I can say that when you're facing death - whether it's 5 years or 5 months, 10 years, 17 years, 30 years... you can figure

17 Years for Gary Quick

out for yourselves how important it would be. An almost euphoric feeling of air actually being inhaled into the lungs, food tasting better, feeling hungry again, not feeling constantly cold - not feeling constantly tired, having new found energy and motivation. And of course being able to get back into the live music scene which was the most important of all to me...

Anyway, after this 5 year period of amazing quality of life, chronic rejection took over and put me in hospital for a 9 week admission. During this time I lost a lot of weight and a lot of lung function - neither of which ever returned - but I lived through it and still to this day have been able to be involved in the live music scene - nothing else matters...

BUT - this is not about me - it's all about all of you and how you could help other people in similar situations to what you've



just read about. As I mentioned earlier, this story is being shared with you in particular because you know who I am today. I AM NOT an advertisement in a brochure or newspaper. I AM NOT a useless online pop-up advertisement

I AM NOT a letter in your mail box asking for your help. I AM NOT a stranger knocking at your door asking for donations. So here is the favour I ask of you: Become an organ donor. Please. Donate your organs when you no longer need them. It's painless for you, your organs will no longer be of any use to you, but will definitely be extremely beneficial for others who will appreciate your generosity. Whether recipients could gain 5 months or 30



years of enhanced quality of life doesn't matter...

If you would like to help, all you need to do now is click on the link below and follow the instructions:

<http://www.donatelife.gov.au/decide>

Believe it or not - I think I'm done.

Thanks to you if you managed to read this far

Thanks to you if you learned anything

Thanks to you especially if you share my message of donor awareness with others

Thanks to you especially - my anonymous donor family.

HLTTV's Donate Life Week Campaign

Our Vice President, Camille Condon, discusses some small things you can do to be part of the HLTTV's DonatLife campaign. Some speech bubble campaign photos appear in

this issue.

DonatLife Week 2016 is almost upon us, and this year, all of us here at the HLTTV want to issue our members, supporters and friends a fun little challenge...

The official theme this year is 'What are you waiting for?'

What we love you to do, is to go to the HLTTV website, and choose a downloadable speech bubble sign. There are different versions to choose from depending on whether you are a recipient, living donor, donor family, or friend/relative.

Change the text in the text box, print out your sign, and then take a fun selfie shot to share on social media during DonatLife Week from the 31st July to the 7th August.

Use the official hashtags **#endthewait** and **#donatlife** and make sure that your social media post is set to 'public' so that it can be picked up by the official DonatLife social media feeds.

To give you a few ideas for your own selfies, our fabulous committee members have taken some to share with you here.

If you would like us to feature YOU and your speech bubble selfie on the HLTTV Social Media Channels (Facebook, Twitter, Instagram) during DonatLife Week, please email your photo to Camille vicepresident@hlttv.org.au

Link to speech bubbles:

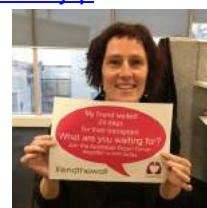
<http://www.hlttv.org.au/organ-donation/donate-life-week-2016>

Link to DonatLife #endthewait campaign live feed

<http://www.donatelife.gov.au/end-the-wait-campaign>

Link to register online

<https://www2.medicareaustralia.gov.au/pext/registerAodr/Pages/DonorRegistration.jsp>



Rebecca and David: Love on Tour

Rebecca Berry and her fiancé, David Floyd, participated in this year's Tour de Transplant. Rebecca, a double lung transplant recipient, had also participated in the 2014 Tour. The Circuator asked this couple about their Tour de Transplant experience.

Rebecca

My name is Rebecca Berry and my life was saved by my donor in September 2012 after my double lung transplant. Not a day goes by where I don't think of my donor family and how grateful I am.

I grew up in a coastal town in South West Victoria called Portland. I have a bubbly personality, love to help others, am creative and since transplant, I now love coffee! I'm engaged to the love of my life, David. Our petting Zoo as we call it contains 3 dogs and 2 cats.

I struggled through childhood which was thought to be asthma. I was diagnosed with a lung disease, bronchiectasis, when I was 20 and seemed to be fine until not long after my 28th birthday when the doctors found I also had Pulmonary Hypertension. I was told I'd need the transplant within 2 years, 2 months later, I needed it. I wasn't even on the waiting list. I was really lucky. I had days to live. A donor was found only 4 days after being on the list as 'high priority.'

I am now better than ever and have done a lot of things that I never thought were possible before transplant. Walking my dogs was the thing I was really looking forward to doing. I've tried ice skating, walked

around the whole of Dubbo Zoo around 6 month after transplant, rode not 1 but 2 Tour de Transplants, and have many more things on my post transplant to do list.

Why did you choose to participate in HLTTV's Tour de Transplant in 2016?

I chose to participate in Tour de Transplant 2016 for another challenge post transplant. Also the 2016 Tour de Transplant started in Warrnambool which is only 1 hour from my hometown of Portland where I was born and raised

How did you feel about the Tour leading up to it?

I felt confident but also a little nervous. I knew before the Tour that the Great Ocean Road has hilly and winding roads so that was always in the back of my mind. I just stayed positive knowing no matter the terrain, I'd do my best.

How did you prepare for the Tour?

Training rides on both bike tracks and roads. Made sure my bike was serviced and ready to get on the road.

How did you manage fundraising for the Tour?

I'm in a local walking group, The Altona Adventurers (you can find us on Facebook) and I mentioned it to the founder of the group and a now very close friend of mine, Ronel, about it. She organised a group 'celebration of life' walk and a picnic. I gave a little talk about the Tour and the HLTTV and what we do and handed out flyers. A journalist, Melissa, from the *Around Altona* newsletter came

along and did a story about the walking group and my fundraising. We are now also friends.

I handed out flyers to family and friends everywhere I went, posted links on Facebook and even held a BBQ in Portland on Saturday morning. I had about 15 money tins in shops of Portland for donations. I did talks for Portland Neighbourhood House and also the Portland Probus Ladies.

Was the Tour what you had expected?

Yes and no. I expected it to be challenging and I didn't expect the inclines to be as big as some of them were. It was definitely fun, rewarding and the views were absolutely breath taking.

Having participated in the 2014 Tour, what were the differences between the two tours?

Apart from the 2016 Tour route being a lot shorter, 600kms compared to 1,100kms in the 2014 Tour, it wasn't a lot different. We had a few different riders this year but many joined in from the previous Tour too which was great. I think the 2016 Tour was a little more challenging being on the coast where the wind tried to make enemies with us and the inclines seemed more challenging too.

Did you manage to improve your performance from the 2014 Tour?

I felt stronger and knew my bike better this Tour even though I did more kilometres in 2014. I seemed to struggle more on the inclines in 2014 than I did during this Tour. I felt



I could tackle the inclines better this year but they still aren't my favourite.

What was it like having David as a fellow rider for the Tour this year?

Amazing. Being able to spend time with my fiancé, David, both on and off the bike was great. We were both able to experience the Tour together while doing our part for a brilliant cause.

Who has been your biggest supporter for the Tours (2014 & 2016)?

My number one supporter would definitely have to be my amazing fiancé, David. David has been there for me before and after transplant and continues to be amazing and supportive in everything I do or dream to do.

My parents, Raymond and Colleen and my little sister and brother, Carla and Scott are equal first. They, just like David, would drop anything to help me or support me in any adventure I want to do. The rest of my family and friends have also been super supportive during both rides. I've been told many times by some that I'm an inspiration to them.

What does the Tour de Transplant mean to you?

Tour de Transplant to me means helping. Helping those who need the Second Chance Accommodation Program and to be in a place where they can be close to their families in time of need.

My dear friend, Ann, passed away 18 months after her double lung transplant. She lived 3 hours from The Alfred Hospital and had to travel with her husband a lot for appointments and check-ups. Unfortunately, the accommodation program wasn't available at the time of Ann's transplant and they spent a lot of money on hotel accommodation. Now the program can help those like her. I want to help others from regional and county Victoria and

from other states to be able to use our program and stay close to their loved ones.

David

Almost 28 years ago I was thrown into the desert of Bourke(NSW) Had me a sick Father and a Mother who worked hard to keep us three kidlets alive.

I cared for him right up until he passed away, then I cared for my



sister who had an interesting bout with schizophrenia. Then I cared for my brother who has the same ailment the old man had, (cardiomyopathy) but you'd not know it if you met him ... today's medicine is quite something.

So you can say I'm pretty good at caring for the unwell I guess; which mind you came in real handy for Rebecca Berry about 4 years ago. Lovely girl I met on an online videogame about 8 years prior, she'd taken a liking to me and somehow convinced me to move to Melbourne from Perth. Well let's just say things went south very fast after I moved in and she was happy

to have me and my ability to care around.

Sometime after that little hiccup I put a ring on her finger and now I'm studying one of those fancy degree's at ye 'old Academy of Interactive entertainment so I can put these weird creations I have in my head onto your TV.

Why did you choose to participate in HLTTV's Tour de Transplant in 2016?

Well It was all Rebecca's lovely idea to get me involved, I personally am no athlete, nor have I ever signed up for anything like the tour . But a dear friend Bob Bumpstead (whose wife Annie Bumpstead received a double lung transplant around the same time as Rebecca but unfortunately passed away a couple of years later) offered to pay for part of the registration and that set in my mind a cause I wanted to stick to, I wanted to ride for Annie's sake , as a Maffra resident she used to have to travel 3 hours post transplant just to get to the clinic sometimes.

There are a lot of people that spend so much time traveling and spend so much money on accommodation I just wanted to do my part to help them.

How did you feel about the Tour leading up to it?

I was quite excited to be honest, I enjoy riding and the previous group rides had been a great experience even with a hangover.

I trained quite a bit so I wasn't too bothered by the actual tour itself, I knew my limits well enough to not be daunted by the distances on the tour and that I would be riding with a lot of supportive and knowledgeable riders.

The one thing that bothered me was hills, I found out on day 3 just how much living in a flat area compromised my training.

How did you prepare for the Tour?

A lot of abusive statements about myself to myself and a 50km commute to Uni 3 days a week.

Rebecca and David: Love on Tour

How did you manage fundraising for the Tour?

I really didn't think the fundraising through enough, also just starting Uni crippled my progress even more, but I had a few generous friends look after me and I managed to put in a bit myself. I may have a secret contract to one particular philanthropic friend that involves me being an exclusive organ donor. But that aside I was something like 350 - 400 short of my goal of 2500, which I think is a good effort by itself but definitely not the best I could have done.

Was the Tour what you had expected?

No ... it was like a week long party broken up by moments of making my body do things it really doesn't want to. At times of the day it shouldn't of even been moving, seriously that lifestyle can't be good for you. 10/10 would do again.

What was it like having Rebecca as a fellow rider for the Tour?

Honestly, made me stress more than I would have liked, and probably aggravated some of the crew leaders a little more than they would have liked with me riding out of form to go check on her every now and then. There was a few moments where it was super nice just to have her around, seeing her moving and having a good time ... in contrast to when I first met her and she could barely breathe.

I only pushed her uphill like 3 times.

What was it like watching Rebecca (for some) on the 2014 Tour?

Rebecca jeopardised her training a lot by picking up a fulltime job a few months before the tour began and the complete lack of hill training made me concerned for her, but after a couple days on tour Bec just got in this mentality where she was just riding for herself, if she fell behind on a hill, she'd just keep putting along until she caught up.

I remember there was one

particular hill before Anglesea where we were waiting for her at the top and she caught up and rolled by, explaining to me " I'm not apologizing, at least I can do this now " or something similar.

This was completely opposite to the usual reaction I expected, made me proud of her

Who has been your biggest supporter for the Tour?

A guy named Dave Toles who traded a large sum of money as a donation for first dibs on my liver.

Also Bec, Bec was great at getting me out of bed and keeping me company for a few of my training rides.

What does the Tour de Transplant mean to you?

A chance for the underprivileged and the location challenged to have a better time post transplant instead of worrying about bills and accommodation and when they'll get to see their loved ones next. Something like "riding a bike puts families close to the Alfred" doesn't really seem philosophical or correct but that's what it means to me .. the fact that a bunch of guys and gals can get together and push some pedals and raise as much money as they have is truly amazing.

It's also a spectacular event, seeing so many people get together for such a great cause, and where else on earth would a little champ like Matty Orchard get to Ride with a big champ like Phil Anderson.

Even with Ian Stubber being the event photographer I had an incredible time and look forward to riding the Tour de Transplant again.

Buddy Program

We are looking for people post-transplant to volunteer for our new buddy program! People who are waitlisted for transplant will be given the option to take part in the program and be matched with a volunteer 'buddy'. This initiative aims to assist those pre-transplant with answering any questions or concerns they may have around the transplant process, and to provide moral support by sharing your own experiences.

If you'd like to become a buddy, please contact Carla at patientsupport@hlttv.org.au.

New HLTTV lapel badges and membership information



HLTTV have new lapel badges! Purchase yours now for \$5.

A reminder that membership payment for the 2016/17 financial year is due. All members who renew by **31 July** will receive our new HLTTV lapel badge for free.

New members will also receive a lapel badge in their Welcome Kit.

Remember - your membership fees help us continue the good work that HLTTV does for people waiting or who have had a heart and/or lung transplant.

Donate Life Week 2016

Everyone who reads the Circulator is aware of the need for organ donation and understands the life-saving and life transforming potential that organ donation has. In Australia there is a body responsible for the delivery of a programme to improve organ and tissue donation and transplantation outcomes in the country; this body is known as the Organ and Tissue Authority and the network tasked with doing this at a state and territory level is the DonateLife Network. Each state and territory has a DonateLife network which consists of collaboration between Medical directors, DonateLife agencies and hospital based nurse specialists in organ and tissue donation. The most sustained and public campaign for organ donation coordinated by DonateLife is its annual DonateLife week. This campaign is aimed at raising awareness of the need for organ donation and the importance of signing the Australian Organ Donor Register (AODR).

DonateLife has encapsulated the process behind encouraging people to sign on to the AODR with its three word slogan of Discover, Decide, Discuss. This first idea "Discover" is one that invites people to inform themselves about organ donation and to get to know the facts about organ donation, a necessary step considering that there are many myths that proliferate about the process. The second idea is straightforward, "Decide", after understanding the facts about organ donation there is a choice to be made about whether one wishes to be an organ donor, the "Decide" step does not push one way or the other but promotes the idea that the decision should be made armed with the facts. "Discuss" is one of the most important steps in the process because of the research that shows how much the organ donation rate improves when loved ones know the wishes of the deceased with respect to organ

donation; it increases the chances of a decision to donate the organs of a loved one by 15%.

As beneficiaries and potential beneficiaries of organ donation, whether indirectly because someone close to us has had, or is waiting for, a transplant or we have had or are waiting for a transplant, we are in a position to make powerful statements about the difference organ donation makes. I encourage all of you to think about how you can spread the DonateLife message during DonateLife week.

DonateLife has some suggestions for things you can do to help encourage more people to join the Australian Organ Donation Register, here are some:

There are plenty of ways you can show your support and encourage Australians to register their donation decision on the AODR and discuss their decision with their loved ones during DonateLife Week – this might be in your workplace, the local media, on your Facebook and Twitter pages, local schools, hospitals and in your community.

- Share your message on social media
- Promote DonateLife Week in your community
- Encourage registration in your workplace.

Share your Message on Social Media

Facebook

Like and Share the DonateLifeToday page on Facebook.

You can also motivate people to register their donation decision online during DonateLife Week by encouraging your friends and family to engage in online discussions, posting pictures from DonateLife Week events, and by sharing updates and information. Or you could upload a DonateLife Week banner to your wall or in the status update and encourage your friends to do the same.

You can also add your decision to be an organ donor on Facebook as a 'life event'. Simply go to your profile and under the About section, add a life event and chose Organ Donor. This is another way of sharing your donation decision with your family and friends.

We encourage you to post on your Facebook page. During DonateLife Week your message could be something like:

Take time this #DonateLife Week (Sunday 31 July – Sunday 7 August) to join the Australian Organ Donor Register online and discuss your donation decision with loved ones. Discover, decide, discuss organ and tissue donation. Check out donatelifegov.au for info about becoming an organ and tissue donor. #endthewait

OR

Knowing that my loved one was a registered donor helped us make the decision to proceed with donation. Discuss your decision with your family this DonateLife Week. #endthewait #havethechat donatelifegov.au

OR

It's DonateLife Week (Sunday 31 July – Sunday 7 August). Discover the facts about organ and tissue donation, make and register your donation decision on the Australian Organ Donor Register, and 'have the chat' with your loved ones about your donation decision. #endthewait donatelifegov.au

OR

1500 Australians are waiting for a life-saving transplant. Please register as an organ and tissue donor this DonateLife Week #endthewait donatelifegov.au

OR

I registered on the AODR and just had the chat with my family that could one day save a life. This DonateLife Week share your organ and tissue donation decision with your loved ones. #endthewait @havethechat More information at donatelifegov.au

You can also encourage your supporters to become DonateLife Facebook fans.

Tag a friend and help spread the word!

You'll find DonateLife's Facebook page at: facebook.com/DonateLifeAustralia

Instagram

Follow @DonateLifeToday on Instagram. Post photos of your DonateLife Week event. (Remember to tag @DonateLifeToday in any images you post)

Twitter

Follow @DonateLifeToday on Twitter.

Donate Life Week 2016

You could also promote DonateLife Week using Twitter by tweeting:

I registered my donation decision online on the AODR during #DonateLife Week (Sunday 31 July – Sunday 7 August). What are you waiting for? #endthewait

OR

I registered & had the chat that could save lives! Share your donation decision with your family this #DonateLife Week (31 July – 7 August) #endthewait

OR

I'm one of 1500 Australians waiting for a life-changing transplant. Please join the AODR online this #DonateLife Week #endthewait

Tweet about DonateLife Week events that your followers may be interested in. You can find out about upcoming DonateLife events at donatelife.gov.au/news-events/events

DonateLife Week Hashtags

Make sure you include these campaign hashtags when posting or tweeting about your support for DonateLife Week:

#endthewait #DonateLife
#organdonation #havethechat

Hashtags can be used on Facebook, Twitter and Instagram.

Hashtags are like keywords that can be used to organise posts or tweets. They facilitate the searching and grouping of posts that contain the same keywords or phrases.

By including your hashtag in a post or tweet, you are automatically joining the conversation surrounding that tag. Your post will appear in a feed along with all other posts containing the same hashtag.

Below is an example of a tweet using DonateLife Week campaign hashtags:

Donate Life Today @
DonateLifeToday Discover, Decide, Discuss: Register your decision online today to transform the lives of 10 or more people #endthewait #DonateLife #organdonation

Promote DonateLife Week in your community

- Organise a community event or registration drive by having an information stall in your local shopping centre or other major community hubs in your area to a fun run with local sporting groups.
- Add a DonateLife banner to

your Twitter or Facebook page and encourage your friends and followers to register their donation decision. Remember to include a link to the AODR.

- Encourage people in your community to use and display DonateLife materials and registration brochures (schools, sporting groups, universities, libraries etc.), as well as on their own websites and social media.
- Encourage local libraries and councils to promote their support for DonateLife Week and provide them with links to DonateLife Week materials.
- Use the DonateLife Week 2016 materials at any public or professional activities that you have planned.
- Share information about your religion's or culture's position in support of organ and tissue donation
- Call your state DonateLife agency and arrange a talk about the importance of registration and family discussion with your community group.

Below are some tips to help get you started:

- Let us know what you're doing – fill in a DonateLife Week event form and email it to enquiries@donatelife.gov.au for promotion on the DonateLife website and social media pages. u can help raise awareness of DonateLife Week in your community:
- Ring your local radio station to talk about why joining the AODR is so important and how people can sign how to register and save lives visit donatelife.gov.au

HELP PROMOTE DONATELIFE WEEK

Generate publicity

You can help raise awareness of DonateLife Week in your community:

- Ring your local radio station to talk about why joining the AODR is so important and how people can sign up online today.
- Write a letter to the editor of your local paper encouraging your community to register their donation decision on the AODR online today and to discuss their wishes with their family and friends.

- Write an opinion piece for a newspaper or newsletter about making a decision and registering on the AODR. Be sure you include the importance of family discussion of donation decisions.

- Post a blog about why you decided to support organ and tissue donation.

- Contact your local newspaper to organise a photo opportunity to promote one of your DonateLife Week activities

Thank you for your support. Visit donatelife.gov.au to find out what's happening in your area or contact your local DonateLife Agency.

Encourage registration in your workplace

Your workplace is a great opportunity to start a registration drive during DonateLife Week 2016. You can:

- Download a DonateLife Week poster to display on notice boards in staff rooms, staff changing rooms, restrooms and kitchens.
- Organise a morning tea or lunch to raise awareness and encourage registration and discussion.
- Include information about DonateLife Week 2016 in newsletters or the intranet including a link to the AODR.
- Display registration brochures in your staff room or lunch area.
- Encourage colleagues to use the DonateLife Week email signature images.

Promote DonateLife Week on payslips

You can use the following text on payslips to help promote DonateLife Week 2016:

This DonateLife Week (31 July – 7 August 2016) join the Australian Organ Donor Register online and discuss your decision with your family and friends. To find out how to register and save lives visit donatelife.gov.au

Support Buddies Needed

We are all familiar with the transplant rollercoaster. The ride begins before you even realize – you are already ill but your quality of life starts to slip, either rapidly or with a steady yet slow decline. Then begins the slow build of meetings and consultations, assessments, poking, prodding, a constant stream of new faces and new issues that must be dealt with. Of course for others this process is frantic, something that happens in the background while they struggle with what may be their last few moments.

But we cannot ride this rollercoaster alone, we must bring others with us. Having an excellent support network is a vital part of transplant that sometimes gets forgotten in amongst the medical mumbo-jumbo and immensity of the situations we find ourselves in. We all bring family, friends and carers – they sit patiently in waiting rooms or by bedsides and fight their own battles (even just the boredom of seeing the gym waiting area three times a week for hours at a time). Those who support us need their own support as well.

Post-surgery, we are all given the opportunity to connect with others post-transplant and their various carers. I loved being in the waiting rooms at clinic, or in the gym, or even waiting for a bronchoscopy. To look around and hear people openly discussing their own rollercoasters, to see the camaraderie between recipients and carers some of who have been in gym or education together, even others that have never met until this moment. We can form strong bonds within our little community. It is a fantastic feeling to find people who you can relate to, people who you can compare experiences with, ask for advice, or even just complain to!

Looking back on my own transplant ride the only thing that left me wanting was a lack of community pre-transplant, and I have heard similar musings from other

recipients and their families. There are certain questions and concerns that only another recipient can understand and this is what ties us all together. This is why we have decided to start a 'buddy program' – where people pre-transplant are given the opportunity to meet with or talk with someone who is post-transplant so that they can get a first-hand account of the journey and hopefully feel more secure going forward. If you would be interested in volunteering as a buddy, please contact me via email.

I was very lucky to find my own support within the HLTTV, and the strong sense of community we encourage is the reason I became a member. The HLTTV aims to provide a place where recipients and all of their supporters can meet with each other and bond over their shared experiences. Since becoming the patient support officer I have been able to share my experience and have had the honour of hearing other people's transplant journeys. I am here to offer support and advice to everyone if it is needed. So if you find yourself with questions, needing someone to talk to, or even just want to vent about the little things that come with transplant feel free to contact me for a chat.

Transplant is a heavy and life-altering process for all involved that consumes much of our time and energy and it is up to us to support each other through these times. Whether it is within your own support networks or in the wider transplant community, never hesitate to reach out for help or advice.

I don't think this rollercoaster ever truly finishes, but there will always be others to ride with you.

Carla Bondini - Patient Support Officer



Heart and Lung Transplant Trust (Victoria)

Our Vision, Mission & Values

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.

Become a member now



Heart and Lung Transplant Trust (Victoria) Inc.

Membership Form

Name:

Partner's name (if applicable):

Address:

Postcode:

Telephone:

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 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.)

Lung/s	Month	[]	Year	[]
Heart	Month	[]	Year	[]
Heart & Lung	Month	[]	Year	[]
Other (please specify)	Month	[]	Year	[]

Are you happy for this information to be included in 'The Circulator' newsletter 'Transplant Anniversaries' each year? 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 Victoria 3004

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

Transplant anniversaries - we wish you many more

August

Heart:

- Ian Ashby, 1997
- Domenico de Maria, 2014
- Neville Eyre, 2002
- Darren Moyle, 2010
- Thomas O'Driscoll, 2012
- Demir Terziu, 2008

Lung/s:

- Geoff Bock, 2015
- Stephen Kinson, 2012
- Phillip Laffan, 2015
- Catherine Liddell, 1997
- John Mills, 2008
- Sivaraman (Yamuna) Sivapi-ragasam, 2011

September

Heart:

- Lloyd Honeycombe, 2000
- Monty Kleiman, 1993
- Greg Maroney, 2014
- John McLean, 1991

- Sammi Tabone, 2009

Lung/s:

- Shirley Aisbett, 2008
- Rebecca Berry, 2012
- Gillian Annette Fleming, 2012
- Angus Harrison, 2015
- Gloria Lancione, 2015
- Martina McArdle, 2009
- Flynn O'Malley, 2015
- Hassell Rutland, 2009
- Louisa Walsh, 2010

October

Heart:

- John Campbell, 2008
- Phillip Felman, 2005
- David Finlayson, 2015
- Robin Oliver, 2000
- Jeffrey Priest, 2008
- Peter Triffet, 2003
- Libero Vila, 1992
- Janet Williamson, 2009

Lung/s:

- Margaret Banks, 2015
- Kristan Braun, 2015

- Bill Carkett, 2002
- Janet Johnson, 2011
- Agnes Russell, 2014
- Valerie Ann Shentzer, 2011

Heart and Lungs:

- Claire Stubber, 1996

Please Note: If you or your loved one has had an attribution made in error or you no longer wish for the anniversary to appear in *the Circulator* please notify the membership officer at:

membershipofficer@hlttv.org.au

If you have sent notice to any other address within the past year please send a reminder email to the membership officer.

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.

Service of Remembrance 2016

Our former editor, Gaylynn Pinniger, attended DonateLife's Service of Remembrance for 2016 and reports here on the event.

Held on Saturday 28 May 2016 at RMIT (Storey Hall) Melbourne

This year marked 25 years since the first Service of Remembrance. Mrs Celia Browne, who was responsible for the organization of the first Service of Remembrance, explained that she conceived the idea for the service in an effort to negate the harsh criticism in the media that transplant recipients didn't appear grateful enough. The first Service was held at St Paul's Cathedral and she said that it was beyond her expectation that the Cathedral would be full. Celia first became involved because one of her sons, Geoff, had health problems from an early age and was not expected to survive. Amazingly he received medical treatment that took him through to having a kidney transplant at age 19. Geoff is now 44, married and proud father to a 4 year old daughter. Sadly, Celia's other son, David, was killed in a motor bike accident. Celia and her family requested that David become an organ donor, and although he was unable to donate his organs, he was able to donate tissue.

The Service of Remembrance has changed in format and venues over the years, but it still continues to provide a forum for acknowledgement of and gratitude to donors and their families. It is also an opportunity for all those touched by organ and tissue donation to meet with others whose lives have also been impacted by this experience.

Donors were also honoured by another speaker Mr John Lowe speaking on behalf of his wife Louise, who as a donor, has helped a number of people.

The medical community was represented by Ms Bettina Clark, Donation Specialist Nursing Coordinator with DonateLife Victoria based at the Austin Hospital. Bettina has been in the donation sector for 8 years and was on the original Donor Family Support Working Group.

The stories shared of transplantation this year were both of young children. Mr Greg Shah told a heart-wrenching story on behalf of his daughter Sienna, a young corneal recipient. He was accompanied on stage by his wife, Sienna and her twin sister and their younger brother. Much of the room was brought to tears by the story of baby Maisy who had a heart transplant at the tender age of 2. Maisy's mother, Ms Michelle Bodinnar told us of the many operations Maisy endured, and the fear she felt as a mother having to hand her baby girl over to surgeons so many times. Now 5, Maisy has made a remarkable recovery much to the relief of Michelle and her family.

Ms Bernie Dwyer, National Training Coordinator for the Organ and Tissue Authority was again the emcee for the service and spoke beautifully about the unique experience and bond between donor families and transplant recipients. For over 10 years Bernie has been a key contributor to organ and tissue donation in Victoria as both an Organ Donor Coordinator and a Clinical Manager.

Beyond the Bathroom

Choir provided the music. Songs chosen were Stand By Me by Ben E. King, Only You by Yazoo and Bella Mama (a song from Torres Strait Islands) as attendees were invited to light a candle for remembrance.

An enjoyable afternoon tea followed and I had the opportunity to speak to a number of donor families. A father had especially come from Tasmania just for the day to honour his daughter who was a donor. I also caught up with a number of transplant recipients, including HLTTV members who attend regularly. Karen (heart transplant) and Christine (double lung) attended for the first time. Christine travelled from Tasmania. Karen and Christine became friends during their transplant journey and it was a great opportunity for them to catch up.

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

-Gaylynn Pinniger

HLTTV Committee Meeting

Date: Tuesday 9th August

Time: 7:30 pm

Place: Seminar room, level 5, Centre Block.



You can also join members of the committee for an informal get-together at 7pm in Alf's cafe.

All welcome!

New life members

3 special people have been nominated as life members to recognise their services to HLTTV. Congratulations to Jon, Martina and Gerry – we appreciate your hard work and are very grateful.

Jon Rolfe (Chairman, Second Chance Task Force)



Jon's dedication, passion and persistence have ensured that both the 2014 and 2016 Tour de Transplant (Tours) were up and running from scratch and have raised an extraordinary \$440,000. Jon's project management skills have ensured that no detail was missed with over 900 items in the 2016 project plan. He used the 2014 experience to improve the 2016 Tour. Nothing slipped through the cracks and short cuts/omissions were never considered. Jon was adamant that the Tour had to be the best possible experience for riders, sponsors and volunteers. Much work was required in securing sponsorships, ordering the jerseys, gilets, caps, shirts as well as organising permits from relevant local councils and approval from Victoria Police. In addition, he was responsible for media coverage securing a media firm, giving radio interviews and beating our media coverage by a long way. He was also responsible for developing the technology behind the Tour such as the website and setting up the fundraising. Jon has worked the equivalent of a full-time job to ensure the Tour's success and the HLTTV Committee is very grateful.

Martina McArdle (Committee Member, HLTTV)



Martina was a key to the success of the Tour by being a dependable, "go-to" person for lots of running around, sorting banners/posters, printing, delivering, calling riders about fundraising, following up RSVPs, sourcing many silent auction prizes, helping to run the Geelong dinner, involving Shaun as a last minute volunteer driver (to replace Russell) and again spending many, many volunteer hours to complete all the necessary Tour tasks.

Gerry Hanily



Gerry MC'd all of the mini-events related to the Tour but in particular he also videoed every day, sourced nearly all the main auction prizes for the Geelong dinner through his extensive network, was the main KPMG liaison, called many of the riders to follow up on their fundraising, spent countless volunteer hours over the last 14 months organizing and helping the Chairman with the many Tour tasks.

Other life members include John Bisiach, Richard & Pru Metzke, Wendy Moule, Felicity Nolan, Gaylynn Pinniger and Sue Tamblyn.



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 providing discounts or supporting us in other ways.

Email our President, Louisa, via:
president@hlttv.org.au
to find out more!

The Circulator – July 2016

2016/17 membership renewals now due

It's the new financial year and that means membership renewals are now due.

All members were sent reminders and we have had a fantastic response so far.

Your \$15 makes a difference! Complete the renewal form in this edition or renew online - <http://www.hlttv.org.au/about-us/renew-membership>

Contact: membershipofficer@hlttv.org.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 Claire by email | claire@hlttv.org.au

Items for review can be posted | Editorial team C/O PO Box 25036, Melbourne, Vic, 3004.
