

the Circulator

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

Spring Edition | 2019 | Issue No. 97



*Our 25th Anniversary
was a celebration!*

Care from Caity...
an appeal promoting
a young woman's
legacy about life

Community Enterprise
Foundation™ partners
with Alfred Foundation
to honour the memory
of Caity Cuthill. [p3]

*Fundraising for
a great cause...*

Funds raised at our 25th
Anniversary Dinner
will ensure the viability
of HLTTV's Second
Chance Accommodation
Program (SCAP)
supporting regional and
interstate families [p8]

*Sacrifices and
challenges can be
profound caring
for your child...*

Mother and daughter,
Kerren and Ammie Boyd
share their experiences
on a rollercoaster called
leukemia and multiple
lung transplant [p13]



SAVE THESE IMPORANT DATES
HLTTV AGM – 12 NOV 2019
HLTTV XMAS BBQ – 24 NOV 2019
LOOK FOR FURTHER DETAILS OF THESE EVENTS INSIDE

President



Special guest, Alfred Professor David McGiffin

What an action packed three months it's been since the last Circulator!

We held our fabulous *Silver Anniversary Celebration* on 31 August, and it was a success in every way possible. The sold-out event raised in excess of \$13,000 – enough to subsidise one apartment for a whole year, and cover many, many emergency financial assistance grants for HLTV members.

It was a highlight to hear from our guest speaker cardio-thoracic surgeon Professor David McGiffin, who was kind enough to speak at our event literally after spending most of the day undertaking transplant surgery.

Professor McGiffin highlighted how much transplant is a team effort from start to finish, and how the two critical factors for a transplant are a brave recipient, and a generous donor.

I'm so grateful to our many, many wonderful sponsors and supporters – those that donated incredible auction items, and those who bid fiercely in both the silent and live auctions. With items including a champagne yacht cruise, unique Aboriginal art and luxury accommodation packages, our guests were spoilt for choice.

As always, our volunteer crew worked so hard to make the event wonderful – while it takes a full team to pull together an event like this, I must make special mention of committee

members Martina, Maarit, Adam (our talented MC), graphic designer Graeme and our 'bank' for the evening, David.

Honorary mentions to Fiona for her wonderful floristry work on table centrepieces, and Wanda who was crucial in getting the silent auction items organised.

An incredible effort from people who all work full-time and somehow fit this into their 'spare' time. What do they say? *'If you want something done – ask a busy person.'*

Also, worth noting in the last quarter we were successful in our application for a \$15,000 grant from the *Care for Caity Foundation*. We'll use this grant to reduce the waiting list for the highly sought *Second Chance Accommodation Program*. You can read more about Caity and her wonderful legacy (opposite).

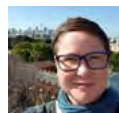
Fundraising and event efforts from our committee are particularly remarkable given we're currently short quite a few committee members. With our AGM coming up on 12 November, if you like what we're doing – join us and help make things even better!

All positions become available, but we're particularly in need of a Vice President (or nominate for President if you're getting sick of me!) and a dedicated Patient Support officer.

More information about the time and location of the upcoming AGM, and where to access committee nomination forms, can be found on page 4 – we welcome you to come along.

I look forward to seeing you at our upcoming Xmas BBQ (it's almost that time already) on Sunday 24 November and wish you good health as we move into the warmer months.

Yours in good health,



Belinda MacLeod-Smith
President, HLTV



VALE Tony Allan

Tony celebrated 25 wonderful years post transplant in April 2019, just weeks before he passed away on 14 May after a short battle with brain cancer.

The very successful transplant allowed Tony to achieve many milestones including walking our daughter down the aisle, the birth of four wonderful grandchildren (now teenagers) and six most enjoyable trips overseas.

Tony also enjoyed volunteering at Deakin University, Geelong as a 'guinea pig' for the medical students and speaking for *Donate Life* about his transplant at many events. He followed his love for cricket umpiring up until five years ago and also followed North Melbourne football club passionately.

The family and I are ever grateful to the donor family for allowing Tony to achieve all these milestones, and giving us 25 more precious years with him.

Sue Allan

Committee meetings 2019

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

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!

Upcoming events 2019

- **Christmas BBQ**
Sunday 24 November 2019

Caity's enduring legacy of living life to the fullest

Caitlin Edwina Joy ('Caity') Cuthill was born on the 6th June 1990 as the third child to Kerri and Phillip Cuthill, and a sister for Rhys and Rachel Cuthill.



Soon after her birth, Caity was diagnosed with cystic fibrosis, and was managed by the wonderful CF team at the Royal Children's Hospital and the brilliant paediatric team at Central Gippsland Health Service throughout her life.

Caity grew up in the town of Maffra, a small rural town in Victoria. To say that she became 'well known' in the community would be an understatement – over the next 19 years of her life it would be hard to find someone in town who didn't have a story involving Caity in some way. She was memorable to say the least! She had a zest for life and was determined to make the most of every day. Her positivity and outgoing personality made her something of a social butterfly.

One of Caity's most enduring legacies was her determination to not let her illness control her life. She was certainly determined not to miss out on doing the things that her peers were doing. At the age of 16 she enrolled in

TAFE and became a qualified beauty therapist, at the age of 18 she became engaged to her partner and they purchased a house together. Caity was extremely proud of her achievements and spent a lot of time with friends at her house. Her door was always open for anyone.

Caity's health unfortunately deteriorated in her later years to the point where she was required to undergo a double lung transplant. She underwent this procedure at the Alfred on 29th August 2010. This procedure was initially successful, however Caity experienced numerous ongoing complications from the transplant and passed away on 8th May 2011.

Caity participated in numerous fundraising activities during her life, including the CF Jail Break, local fundraising activities, countless 'crazy hair' fundraisers (and some crazy hair styles that had nothing to do with fundraising as well!) *Caity's Story* also featured on television for the Royal Children's Hospital Good Friday Appeal.

It is this legacy that led to the formation of the *Care from Caity* foundation. Having experienced the financial strain that staying away from home long term to support an unwell family member creates, Caity's family decided that her legacy would continue to be one of supporting those in need.

Our goal was to provide assistance for families from Gippsland who were caring for a family member who has received a lung or heart transplant at the Alfred Hospital. Since its creation, *Care from Caity* has been proud to donate over \$20,000 to the Alfred Hospital, which has been used to subsidise accommodation costs for families staying in Melbourne to look after loved ones



The Care from Caity Appeal

The *Care from Caity* Appeal has been established by Community Enterprise Foundation™ in partnership with the Alfred Foundation in memory of Caity Cuthill, of Maffra.

Caity suffered from Cystic Fibrosis and tragically died after receiving a double lung transplant.

Caity was just 20 when she died. She was born with Cystic Fibrosis and spent much of short life travelling up and down the freeway from Maffra to Melbourne for treatment at the Alfred Hospital.

Caity wanted to help other rural Gippsland families of transplant patients who also spend much of their time and funds travelling back and forth to the city for treatment as they wait for or recover from heart and lung transplants.

Your donation will go to the Alfred Foundation who work with the *Care from Caity Advisory Committee* to ensure families and transplant patients receive travel assistance and accommodation costs as part of their treatment for Cystic Fibrosis or organ transplant with the Alfred.

While Caity has tragically passed away, her dedication to supporting others with Cystic Fibrosis or require an organ transplant lives on.

www.communityenterprisefoundation.com.au/make-a-donation/appeals/care-from-caity-appeal



Alfred physio awarded prestigious fellowship

Any patient who has experienced the care of Louise Fuller can attest her lung transplant rehab program produces incredible results. So it's fitting that Lou has been recognised in a prestigious fellowship program – the *Churchill Fellowship*.

Since 2000, the senior physiotherapist has been developing and researching The Alfred's post-lung transplant rehabilitation program.

In the last six years, lung transplants have almost doubled in Australia – an increase of 46 per cent. Last year, 221 patients underwent the life-saving procedure.

After a lung transplant, recipients are keen to maximise on their second chance at life and return to a "normal" active life. To get the best results, post-transplant rehabilitation is essential.

Lou has successfully expanded the transplant gym to meet the needs of more than 100 lung transplant recipients The Alfred sees annually.

Lou was awarded the *Sir William Kilpatrick Churchill Fellowship* to investigate a variety of post-lung transplant rehabilitation models internationally to help her develop guidelines for Australia.

Only one hundred and fifteen Australians will get the opportunity to travel around the world in 2020 as recipients of the prestigious *Churchill Fellowship* award.

This Fellowship will see her travel to the UK, Belgium, USA and Canada to visit lung transplant centres of excellence. Lou will then work with The Alfred team to develop rehabilitation model guidelines for Australian lung transplant recipients.

Lou hopes to learn new models to improve patient survival, quality of life, participation in daily activity, muscle strength, mobility and return to work and sport. (Courtesy www.alfredhealth.org.au)



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

AGM

Notice of Annual General Meeting 2019

Tuesday 12 November at 7.30pm

5th Floor Seminar Room, The Alfred

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

The business of the annual general meeting shall be:

1. Confirmation of Minutes of the 2018 AGM
2. Presentation of the 2019 Annual Report
3. Presentation of the 2019 Annual Financial Report*
4. Elect officers of HLTTV and the ordinary members of the committee; and
5. Confirm appointment of the auditor for 2019-2020
6. Any special business (if any)

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

The 2019 agenda and minutes of the 2018 AGM are available on our website in the Events, AGM section.

Any member intending to bring any other business before a meeting must notify the Secretary in writing, or by email to secretary@hlttv.org.au no later than 22 October 2019.

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

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

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

If you plan to attend the AGM, please RSVP by Friday 8 November, 2019.

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



@HLTTV

www.hlttv.org.au



HLTTV1

Did you know?

- When the HLTTV *Second Chance Accommodation Program* began in 2012, it supported nine patients/families with two apartments at a cost of \$11,238.
- Some seven years later, during 2018-2019 HLTTV supported 46 regional and interstate families by securing and subsidising eight local apartments and funding a part-time social work assistant.
- With our total financial support running to over \$100,000 each year, HLTTV volunteers and our generous supporters

have worked hard to ensure financial assistance is available for transplant recipients and their families, particularly rural, regional and interstate families receiving their second chance at life through heart or lung transplantation.

- The increase in demand for post-transplant support aligns with the increase in transplantation services at the Alfred. Over the same seven years, Alfred transplants have almost doubled, increasing from 19 hearts and 55 lungs in 2012/13 to 37 hearts and 94 lungs in 2018/19.



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.

HLTTV Second Chance Accommodation Program

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

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

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

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

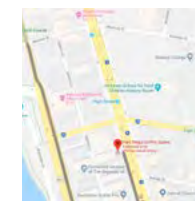
Park Regis Griffin Suites

Phone (03) 8530 1800

Location 604 St Kilda Road, Melbourne

Email griffin@parkregishotels.com

www.parkregisgriffinsuites.com.au



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

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

HLTTV contacts 2019

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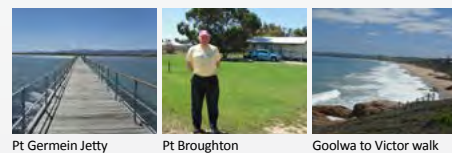
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Celebrating his 1000th official gym session since his transplant in 2008, Andrew Hunt is a HLTV member who regularly updates our readers on his transplant journey.



Pt Germein Jetty

Pt Broughton

Goolwa to Victor walk

I still haven't purchased that rocking chair, yet!

In my previous short stories, I reckoned I wasn't ready for the rocking chair. Luckily for me that remains the case.

After returning to Adelaide in May 2008 after my transplant, I joined the Goodlife Gym at Burnside, where I regularly attended until late in 2014. Since then I have been attending Goodlife at Dernancourt, where I prefer the treadmills.

Power walking has become my passion. I am capable of walking 8 kms in the 59 minute range. This is all walking without breaking into a jog. My PB of 57 minutes and 38 seconds was set in early 2013. However, these sorts of speeds are now beyond me!

I still power walk regularly but find my gym sessions, that also involve a few weights, are taking more out of me as I get older. I usually go to the gym a couple of times per week and also do some street walks and plenty of gardening. In October 2018, I walked from Goolwa Beach to Victor Harbor (two regional seaside towns about an hour south of Adelaide) on a gorgeous day. It's days like those that make me so grateful to be alive!

I'd like to give a shout-out to both the Burnside and Dernancourt gyms. They have both published some posts about my heart transplant, once made me 'Gym member of the month' and raised awareness of organ and tissue donation.

I have recently started a part-time paid role, in the Not-for-profit sector, assisting mature age people with career and employment support.

Overall, I have been very fortunate post-transplant. To date, I have tolerated my anti-rejection medications and had no episodes of rejection. I have had some in-patient stays, including a bout of pneumonia late in 2018.

We haven't done much travel lately, although we did have a few days in Port Broughton recently that included a walk on Port Germein's 1.5km long Jetty.

As mentioned in my last story in the Circulator 2016 (Issue 83), when I am in the gym, I frequently recall my existence pre-transplant when I would become breathless just getting out my chair, my lungs would fill with fluid and I had constant insomnia. My defibrillator gave me a number of timely shocks for VT, I suffered unrelenting dehydration caused by extreme doses of frusemide and the toxic side effects of amiodarone caused me to have my Thyroid removed in early in 2005. I also had frequent in-patient stays and was often off work and felt awful most of the time.

I am 63 and enjoying good health right now. Sitting in my wheelchair outside the Alfred gazing across to Fawkner Park early in 2008, I would never have thought getting to 1,000 gym sessions possible. Officially I achieved this milestone on 9 August 2019, although it was probably achieved earlier if you include a number of manual sign-ins over the years!

All the best to everyone, Andrew and Dana

A random act of generosity

Findex Community Fund via Crowe Australasia (a part of Findex) have generously donated \$2,000 to the HLTV to assist with their assistance programs.

Good things happen to good people could easily sum up this random act of generosity as the day that Colin Dowell, an Alfred lung transplant recipient was celebrating his 3 year anniversary of his successful surgery, Crowe Australasia was randomly drawing a 'lucky door prize' at a NSW Local Government event.

Colin had nominated the HLTV as his preferred charity in case he won. He is pictured below being acknowledged as the winner of the door prize and displaying his nominated charity.

Sure enough, Colin won the door prize and the HLTV were the recipient of his (and Crowe's) generosity.

Brad D. Bohun, Senior Partner – Audit & Assurance at Crowe passed on the pleasure he and his staff derived from their Community Fund being able to make a contribution to the Heart and Lung Transplant Trust Victoria.



How can I claim PARKING CONCESSION at The Alfred?
Enquire on (03) 9076 3244

TRANSPLANT 2019 ANNIVERSARIES



HEART

AUGUST 2019

Geraldine Ashby, 1997
Domenico de Maria, 2014
Neville Eyre, 2002
Glen Jones, 2018
Darren Moyle, 2010
Thomas O'Driscoll, 2012
Demir Terziu, 2008
Dean Thomson, 2009

SEPTEMBER 2019

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

OCTOBER 2019

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



HEART + LUNGS
Claire Stubber, Oct 1996



LUNGS

AUGUST 2019

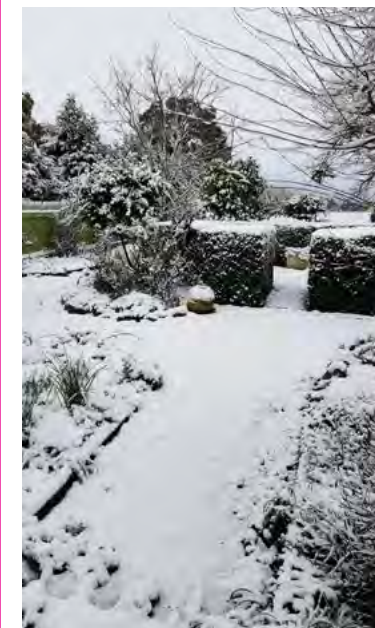
Nicole Barnes, 2017
Stephen Kinson, 2012
Phillip Kaffan, 2015
John Mills, 2008
Sivaraman Sivapiragasam, 2011

SEPTEMBER 2019

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

OCTOBER 2019

James Carroll, 2017
Jane Fletcher, 1993
Brendan Foster, 2017
Sharon Golden, 2017
Judith Hogan, 2012
Carol Huxley, 2012
Janet Johnson, 2011
Agnes Russell, 2014
Valerie Ann Shentzer, 2011
Andrew Weybury, 2015



Xmas in August!

This spectacular scene is the front garden of Eric and Jane Foster in Dean, Victoria during a cold snap in August this year.

Eric was a single lung transplant recipient at The Alfred on 30 January, 2019.



Celebrating excellent outcomes at the Alfred

Heart transplant recipient **Graeme 2019** & Andrea Klemm celebrated the excellent transplant outcomes for a group of recipients that have become friends through their VAD and subsequent transplant journeys (**Rod 2018** & Lynn Pulford, **Bruce 2018** & Lyn McAndie, **Katelyn 2019** & her mum Sharon Morris. Graeme is pictured presenting a unique piece of art he created in his friends' honour to some of the wonderful Alfred Heart Transplant team.

Make a secure donation



GiveNow

Give more, give smarter, give better, GiveNow!

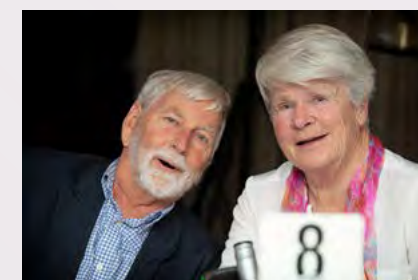
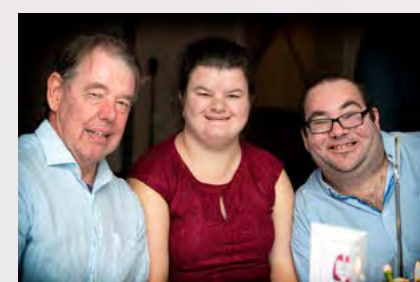
Donations to the Heart and Lung Transplant Trust (Victoria) are fully tax deductible and easy to do using the website below.

Simply follow the prompts.

GiveNow.com.au

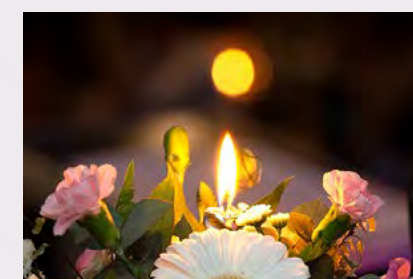


Our group of brave heart and lung recipients at our dinner celebrating their achievements

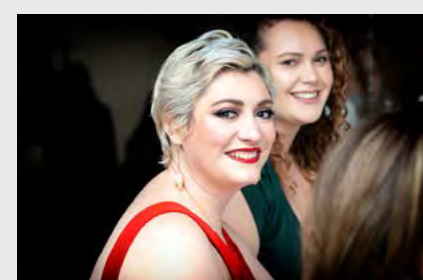


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Funds raised at our 25th Anniversary Dinner will ensure the viability of HLTTV's Second Chance Accommodation Program (SCAP) supporting regional and interstate families.



Heart to Heart House, Barmah Vic

Rest, recuperate, recover

Why not leave the hustle and bustle of the big smoke for a relaxing holiday at Barmah in a house designed to help you unwind and relax?

Approximately six years ago the late Bill Vickers entrusted the *Heart to Heart House* to the Rotary Club of Nathalia and it is very proud to continue what Bill began... a respite home for pre and post heart and/or lung transplant patients and their carers to rest, recuperate and recover.

The Heart to Heart respite house is located at 26 Schier Street, Barmah in country Victoria. It is a modern, all electric, 2-bedroom house with all necessities provided for a comfortable stay.

The bedrooms (1 queen, the other 2 singles) have built-in robes and a television/DVD. The open plan kitchen has all electric cooking. The lounge/dining has a large TV, DVD player and stereo system.

The bathroom is set up for any wheelchair access and there is a laundry with automatic washing machine.

There is an outdoor table with four chairs on the front porch, with a BBQ on the back porch.



Guests only need to take food and personal items as everything else is provided... even books, magazines, DVDs and CDs.

Linen and towels are already on the beds should anyone wish to hire these. Linen hire is \$5 per person, per visit.

Each guest is charged \$15 per night for accommodation (up to a maximum of 6 nights).

Barmah is approximately 230 kms north of Melbourne and is the only town in Victoria which is north of the Murray River.

Barmah is best known as the gateway to the Barmah National Park; it is heritage listed and home to the largest stand of river red gums in the world. The oldest river red gums are over 500 years old and often grow to thirty metres in height.

The Barmah National Park has a fascinating history that can be explored at the *Barmah Forest Heritage & Education Centre* at Nathalia (about 15 minutes by car).

Kingfisher Cruises on the Barmah lakes may be of interest to some guests, as may the punt.

The Barmah Hotel (a very short walk from *H2H House*) serves delicious lunch and evening meals. *The Forest Door* for coffees, lighter meals and takeaway food is next to the hotel.

Echuca is within 30 minutes by car. Tour the old port, with paddle steamers, hotels, shops, a local museum and even a Holden museum.

Other nearby towns include Cobram, Tocumwal, Nathalia,



Deniliquin, Strathmerton, Koonoomoo and Yarrawonga.

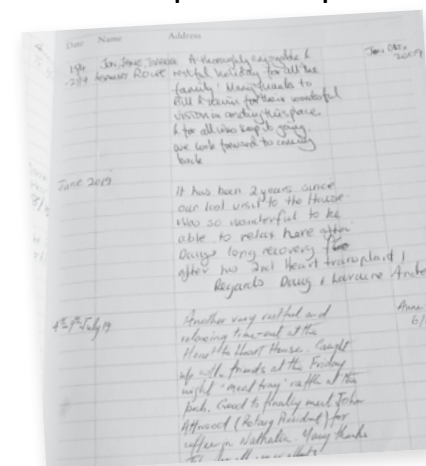
A couple of interesting places are *Cactus Country* at Strathmerton and *The Big Strawberry* at Koonoomoo. At *Ulupna Island*, near Strathmerton, koalas can often be found in the trees beside the Murray River.

There are wineries, cafés, shops, places of interest, tourist

information centres, hotels and museums at some of these towns and Yarrawonga is near Lake Mulwala, where cruises are available.

So, why not leave the hustle and bustle of the big smoke for a relaxing holiday at Barmah? We would be very pleased to have you stay (past guests have raved about the serenity and so enjoy it that they return again and again).

John Attwood
President of H2H committee
Rotarian and past Rotarian president



Get in touch with the Ballarat Support Group

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

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

Members of the group come from all around Ballarat and surrounding areas.

If you live in or around Ballarat and are interested in being part of the group or find out about upcoming meeting dates and locations, please contact:

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

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



For bookings and information

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

Sacrifices and challenges can be profound caring for a sick child

Mother and daughter, Kerren and Ammie Boyd share their experiences on a roller coaster called leukemia and multiple lung transplant

Kerren's perspective

Our family's journey began in 2003 when Ammie, my daughter, fell sick with Leukaemia. Coming to the end of chemotherapy things appeared positive until another serious road-block stood in the way of a full recovery. Things started spiralling when we received news that Ammie was in need of a Lung transplant due to complications.

Nine years later we found ourselves on the same transplant roller coaster, with an even more intense ride than before.

Whilst taking care of my daughter with a chronic illness I encountered difficulties with finances, sibling relationships and parenting, all while trying to maintain a normal social life.

The costs of medications, routine doctor visits and then hospitalisations can be enormous financially and emotionally.

Everyday routines and plans constantly changed as we had no control over where our lives were heading. It felt like decisions made were already limiting the time I could spend with my other children, family and friends.

Focussing time and attention on Ammie, I was less available for the needs of others, I was less patient than what I would normally be. During this time I struggled with dividing my time, I found it exhausting, and I experienced overwhelming feelings of guilt and loneliness even though I had people around me.

I felt like nobody understood what I was going through. I lost friends as they were unable to be a part of my world. I never shared with new people what our life was about as I knew they would never understand. I lived a life of silence. One part of my world was filled with hospital visits and caring for my child and the other part was a world where I tried to forget what was really happening. I lost myself.

It was hard to stay balanced, self care was lost, sometimes I would forget if I ate or the last time I had a shower. I had sleepless nights and spent many nights crying alone.

I wore a mask, every day staying strong and positive for my seriously ill daughter, trying to keep our home life as normal as possible, trying to financially keep our family afloat.

My career was affected and I was unable to keep a full-time job due to the challenge of my commitments. I created my own home business so I could work when time permitted.

As I live my day-to-day life I feel I live in an isolated world, the many friendships I had from school and work I no longer have a connection with.

My two other daughters have made so many sacrifices, missing out on activities and adventures their peers were enjoying. Now the girls are older they are able to venture out and socialise and make up for lost opportunities.

Like many young people, my girls sometimes struggle to express their feelings with one-another causing miss-understandings.

Ammie's perspective

My difficult journey began in 2003 with Acute myeloid leukaemia (AML) when I was 12.

My life was uprooted having to move closer to Melbourne (Bendigo to Gisborne).

I returned to school (Primary) after 6 to 12 months off due to treatment.

I found the 2-year age gap between myself and my peers made it difficult to make friendship connections. I felt so out of place.

School understood and supported my feelings of not belonging or fitting-in and moved me into a higher grade but even then it was hard to get a sense of belonging as it was the middle of the year. As I was in a wheelchair with respiratory conditions I



It was extremely hard work but Ammie's resilience and her family's support were crucial in meeting her medical challenges



Ammie during one of her regular Alfred gym sessions

I like to think that my chronic disease doesn't define me, its not who I am, its only a small part of me.

always felt different because I was limited participating in school activities such as swimming carnivals, camps and athletics.

Leading a relatively 'normal' life like my peers was difficult due to my limitations.

I was diagnosed with *Graft-versus-host Disease* which affected my lungs with *Bronchiolitis Obliterans*.

Transitioning into high school was hard as I felt different to everybody else – I carried oxygen around school, I would have feeding tubes coming out of my nose to assist with weight gain and I needed help to mobilize getting to and from my classes.

I was regularly getting sick and missing out on high school milestones such as Year 7 camp where you could make new, fresh and exciting friendships. This made it hard for me to join friendship groups that had already formed, which made me feel different and isolated. I lost a lot of self-confidence.

It was confronting to find out the only way I was going to have any chance of leading a relatively normal life was to have a 'double lung' transplant.

This was where my life became very different to my friends and anybody around my age of 16.

No longer did I have the opportunity to go to parties and experience a really important period in my teens of discovery, self-expression, friendships, relationships and planning for my future.

Vision-making became a big part of my life with things no teen should have to consider. I was left making life-choices of whether

or not to have life-changing surgery and trying to make the right life-choices to keep myself healthy long enough to be able to have my transplant when suitable lungs became available. I was left looking at the bigger picture.

This didn't only put a strain on my friendships but it also put a strain on my relationships with Chelsea and Hollie, my two younger sisters.

I often had feelings of guilt when it came to mum spending loads of time caring for me and keeping me healthy because more often than not she missed out on doing special things with my sisters such as Hollie's school carnivals, Mothers' Day at Kinder or being able to drop Chelsea to her Year 12 Formal.

After my transplant

I was given a new look on life resulting in a different perspective.

I saw the world through different eyes. I was made to grow up quicker due to the situation I was put in. This formed cracks within friendship groups.

I couldn't go to school for three months because of three-days-a-week rehab at the Alfred as well as having regular doctor's appointments.

During this time I had to avoid the risk of infections resulting in me losing a lot of friends because of their lack of understanding about why I couldn't go to public places like the movies or eating at McDonald's.

This was very isolating. It left me feeling isolated. I felt I was trailing behind everyone else as I didn't even have my L's because I wasn't able to drive.

It was upsetting not being able to finish my school year with my class mates. Having to make the choice to move schools and doing my Year 12 at RMIT with another new beginning and trying to make new friends was very hard.

I found myself not sharing with people who I was or what my background was as I was sick of having the feeling that people became my friend because they felt sorry for me. All I wanted was for people to like me for who I was. I like to think that my chronic disease doesn't define me, its not who I am, its only a small part of me.

After Year 12 I finished two diplomas – *Graphic Design* and *Interior Design and Decoration*.

I started working in the family cleaning business eventually taking over the business. This gave me hope and a sense that my life was going in the right direction. I still had trouble with social settings and making new friends because I think the isolation and choices I had to make as a teen with a chronic illness has taken a toll on my social skills.

I found it hard to feel like people understood what I was going through and how I was feeling day-to-day.

The medications I have had to take have resulted in some side affects including:

- mood swings
- tremors and shakes
- difficulty concentrating and comprehending some things
- memory.

The frustration of the first few months proved very hard as I found myself being short tempered at siblings and mum for no reason, causing fights.

I found myself finding it hard articulating how I was feeling as some days I couldn't express myself clearly .

I found it hard to come to terms with not being able to look towards my goal of working with young children in a child care setting due to the risk of infection.

I struggle with the limited choices I sometimes have in my life. I feel like I have little or no control over what I can and can't do because I have so many things to consider with my health issues.

This leads to frustration and sometimes very unsatisfying feelings of anger.

I still feel like I'm trying to find my purpose in life as I didn't get to do that as a teen or young adult.

I feel as though I should be in a different position in my life, having achieved more. However, I sometimes forget that I have been on a different path and have achieved a great deal in my life – just not what I had expected.

Editor's note

As a parent, caring for any child can be challenging at times. The responsibility of ensuring the physical, intellectual and emotional development and wellbeing of a child is the most important job a parent can ever have.

The escalation in difficulty that a serious illness brings to a parent's responsibility to their child can be overwhelming.

The HLTVV strongly advise any individuals and families feeling under pressure to reach out and talk to one of the many organisations that provide professional assistance, including:

- [Carer's Victoria](#) – an organisation dedicated to social, psychological and financial support for those with caring roles – Ph: 1800 242 636
- Hospital-based social work departments can also be a good place to start – this will depend on service size. Often clinic receptionists and admin staff can provide you with current contact details for social work staff.

Remember, parents and carers need to be strong physically, mentally and emotionally to support the patient.

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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

DID YOU KNOW?
the Circulator editorial team is keen to review and promote 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 circulator@hlttv.org.au
Items for review can be posted to:
Editorial team c/o PO Box 25036, Melbourne Vic 3004



What is a cardiac technologist?

My name is Kathryn and I am a Cardiac Technologists in the Heart Centre at The Alfred

We are a team of 22 skilled staff with Science backgrounds and an interest in all things Cardiology!

The tests we complete are required for assessing heart disease from Transthoracic Echocardiography to Electrophysiology and more.
We often get asked what a cardiac technologist is, and the answer is we are a team that provides a technical service for the investigation, diagnosis and treatment of heart disease.

We carry out tests such as echocardiograms, ECGs and ECG interpretation, Holter monitors (24-hour ECG) and analysis along with blood pressure measurement.

You'll also meet us if you've got a pacemaker or ICD, have had angiogram or other invasive Cardiac CATH lab procedures. We are trained to operate a range of specialized equipment that provides Cardiologists and other medical practitioners data to help treat and care for their patients.

I began my cardiac technologist journey 6 years ago in a small private clinic where I learnt about ECGs and pacemakers. I then started work in our Nuclear Medicine department here at the Alfred Hospital, where I was

involved in the pharmacological stress tests for patients.

Six months later I moved to the Heart Centre where I trained in the areas listed earlier and I'm currently in the middle of finishing my post graduate degree in Cardiac Ultrasound.

In my profession, no two days are the same. What I love about this job is seeing patients on their individual and unique journeys through The Alfred – from VAD patients to our Heart Transplanted patients and even those who we see for only a short time during their stay here.

Our role takes us all around the hospital from the Emergency Department, theatres, ICU and even to Radiotherapy.

Teamwork is crucial in our department and is incredibly rewarding when we collaborate closely to assist with our high-risk patients such as out-of-hospital cardiac arrests and heart failure patients. We work closely with Cardiologists, Cardiac CATH lab nurses and radiographers to make up a very strong team.

The hours I work are pretty consistent, usually 8am till 4.30pm with the odd weekend or weekday On Call for the CATH lab or ECHO.

Your membership counts



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 ☐

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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.hlttv.org.au> and follow the 'Membership' links.

What's your story then?

We're always on the hunt for the truly heartwarming and unique experiences of people who have either been through the life-changing challenges associated with heart and lung transplantation, or have been their carer.

Please ring 0421 327 096 to discuss or email circulator@hlttv.org.au

Remember, people going through this type of medical trauma are often able to gain strength and inspiration from hearing about how other people have met that challenge.



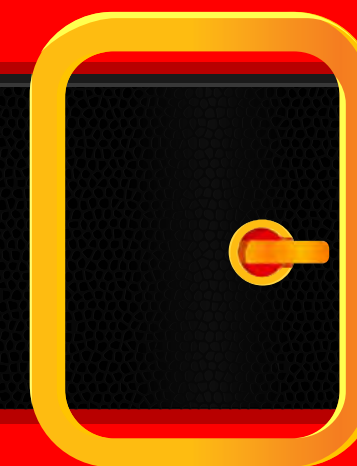
Xmas BBQ

Sunday 24 November, 2019

11.30am – 2.30pm

Fawkner Park

Across from main entrance
to The Alfred Hospital



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

Please BYO nibbles, chairs etc.

Great raffle prizes offered on the day – donations can be left at 5th Floor Reception at The Alfred.

Alternatively, please contact Martina on 0409 957 492 or email martina@hlttv.org.au or maarit@hlttv.org.au



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HLTTV1



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