the Circulator special edition



Tour de Transplant | 2014 | Issue No. 76

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



Early morning shadows race with the riders in the Dandenongs on their second group ride for the Tour de Transplant. Photo courtesy Snaphappy Ian Photography©

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STOP THE PRESS STOP THE PRESS STOP THE PRESS STOP THE ... Easter eggstravanza to celebrate rider return

This year's HLTTV Easter BBQ will be held to coincide with the riders return to Melbourne after 1,100km of hard work. Make a diary note for Sunday, March 30 from 11.30am - we'd love your help to celebrate this amazing achievement.

See back page for full details - contact events@hlttv.org.au for more information. Page 1 Issue No. 76 | Tour de Transplar



Join us for the annual HLTTV Easter BBQ on Sunday, March 30 2014 from 11.30am on Fawkner Park Lawn, opposite The Alfred.

FREE food and drink

We'd love to see all members and supporters on hand to welcome back our Tour de Transplant riders after their 1,100km odyssey.



The bike ride might be the easiest bit...

Message from the Editor

To be honest, this introduction could have been written by someone much closer to the logistics of the Second Chance Task Force, the Tour de Transplant or the Tour de Chat.

Here's the thing. All the amazing, talented, tireless volunteers are really, really busy with the actual event.

Many of our volunteers, transplant recipients themselves, have been working 60-70 hour weeks in the pursuit of creating an incredible, inaugural Tour de Transplant to raise awareness and funds for an incredibly important cause.

The reason

This special edition of the Circulator has been put together to celebrate not just the event, and all the people working together to make it happen - it's a reminder of just why we're all so committed to the cause.

It's important to remember that HLTTV is a non-for-profit organisation whose membership almost entirely consists of patients and carers who have had or are waiting for a heart or lung transplant at The Alfred.

The Tour de Transplant event is to raise money to house patients and carers from country Victoria and interstate (SA, Tas, NT & southern NSW) during their compulsory attendance a minimum of three days a week for three months at The Alfred immediately after their transplant to engage in rehabilitation and medical monitoring.

If you can imagine the physical and emotional stress of waiting

for a transplant, just try to imagine what the financial stress is like for families who must travel far away from friends, families and paid work to spend the minimum three months in post transplant rehabilitation.

While some States provide financial support, it's rarely enough to cover the cover the basic costs of accommodation, which can total more than \$10,000 at a time when transplant recipients really need to focus on recovery.



HLTTV is grateful to, and deeply appreciative of the support of, the following individuals:

Second Chance Task Force

Jon Rolfe, Chairman Martina Appelman John Bisiach Greg Campitelli Jillian Gange Gerry Hanily Maarit Moilannen Matthew Orchard Michelle Sams Claire Stubber

Regional Ambassadors

David Biram - Shepparton Glenda Coulthard - Albury Penny Davies - Bendigo Diane Ferraro - Bright Beth Johnson supported by Wanda and Darren Moyle -Traralgon Stephen Kinson - Ballarat Marg Neilson - Bairnsdale

HLTTV Management Committee

David Hayne, President Louisa Walsh, Vice President Jane Cooper, Treasurer Rebecca Berry, Secretary Vanessa Scott, Membership Officer Martina Appelman Jeff Campbell Camille Condon Belinda MacLeod-Smith Claire Stubber Claude Turco

Website snapshot -Wednesday 25 February

The GoFundraise 'ticker' showing the results of our hardworking fundraisers, volunteers and supporters. Visit our GoFundraise site to see the latest on the ride. www.tourdetransplant.org.au

Sponsors and Supporters

A multi-faceted event such as the Tour de Transplant could not take place without the generous financial and in-kind support offered by the following organisations. The Heart and Lung Transplant Trust, on behalf of all current and future members of the Alfred Transplant family offers our sincere and deep gratitude to the following organisations both large and small:



2XU Anglican Parish of the Parks Campitelli Consultancy JWAM Victorian Police Homicide Squad Cycling Team

Bendigo Osteo Shepparton Osteopathic Clinic Bright Velo Candace Garam - Design & Artwork Ian Stubber - Photography Simon Renn - Massage Fiona Lee - Massage Sam Ira - Video Russell Todd - Driver Richard Russell

Tour de Transplant Incorporating Tour de Chat



The Chat That Saves Lives

At the same time the Tour de Transplant riders are taking on their cycling challenge during 22-30 March, HLTTV volunteers will be taking on the challenge of presenting a nine day organ donation awareness program: **The Tour de Chat - Have the Chat** *that Saves Lives.*

While the 1,100 kilometre cycling challenge acknowledges the 1,100 Victorians who have received heart and lungs since the first transplant in 1989, the route itself passes through towns and communities that are home to many of these transplant recipients.

Our *Tour de Chat* Ambassadors will travel the same route from Melbourne to Geelong, through Ballarat, Bendigo, Shepparton and to the border at Albury.

From there, they'll progress south-east crossing over the Victorian Alps to Gippsland before the final stretch to Melbourne.

Working closely with the DonateLife nurses' network and others, HLTTV organ donation ambassadors will conduct a series of presentations in each location, on the nine day challenge.

This will see ambassadors leapfrogging the riders (not Page 4 literally!) to give a series of talks and presentations on organ donation awareness at local organisations, including schools, sporting clubs and service clubs, on the route of the Tour.

Each presentation will be 30-60 minutes long, and presented by a transplant recipient, who can give the facts about organ and tissue donation and tell their own story.

Sessions to suit you

The information sessions will be dynamic and informative, with lots of opportunities to ask questions.

Of course, education sessions can be adapted to suit any group, and all sessions are free of charge with a range of useful and practical merchandise available for attendees.

If your organisation is along the route of our Tour, and keen for an education session about organ and tissue donation, please get in touch with us.

This project is sponsored by



Australian Government Organ and Tissue Authority



If your school, organisation or club would love this chance to hear inspirational stories from amazing people, then simply contact HLTTV Vice President Louisa Walsh, tel:0427 509 042 **e-mail: vicepresident@hlttv.org.au** Towns and dates can be seen on the right, OR by visiting www.tourdetransplant.org.au





Tour de Transplant/Tour de Chat presents "An evening in your town"

You are cordially invited

Throughout the tour, you have the opportunity to join us for a unique and inspirational evening with Phil Anderson, Australian cycling legend, tour riders and amazing heart and lung transplant recipients.

Included in the evening's entertainment is a three course dinner. Tickets range from \$55 - \$75 per person, and in addition to helping support the Second Chance Accommodation Program, the evening will include:

- cycling legend Phil Anderson speaking about his life on the bike, and achievements at the Tour de France and other professional events
- the inspirational story of a local transplant recipient
- the opportunity to bid on various goods and services in a charity auction
- the chance to understand just how important it is to 'Have the Chat That Saves Lives'
- more information about the reason for all this HLTTV's Second Chance Accommodation Program



Saturday 22 March - Ballarat

6.30pm, George Hotel 27 Lydiard Street www.tdet-dinner-ballarat.org.au Ambassador: Stephen Kinson

Sunday 23 March - Bendigo

6.30pm, Foundy Hotel Complex 366 High Street www.tdet-dinner-bendigo.org.au **Ambassadors**: Penny and Cled Davies

Monday 24 March - Shepparton

6.30pm, Parklake Hotel 481 Wyndham Street www.tdet-dinner-shepparton.org.au **Ambassador**: David Biram

Tuesday 25 March - Albury

6.30pm, The Commercial Club 618 Dean Street www.tdet-dinner-albury.org.au **Ambassador**: Glenda Coulthard

Wednesday 26 March - Bright

6.30pm, High Country Motor Inn 13- 17 Great Alpine Road www.tdet-dinner-bright.org.au **Ambassadors**: Tony and Dianne Ferraro

Friday 28 March Bairnsdale

6.30pm, Bairnsdale Sporting and Convention Centre 117 Great Alpine Road www.tdet-dinner-bairnsdale.org.au **Ambassador**: Marg Neilson

Saturday 29 March - Traralgon

6.30pm, Traralgon Golf Club Princes Highway www.tdet-dinner-traralgon.org.au **Ambassadors**: Beth Johnson supported by Wanda and Darren Moyle

To book tickets for all Tour de Transplant dinner events... You can book tickets by visiting the dedicated web pages for each dinner as listed above, or simply call Jillian on 0431 709 547 to help HLTTV reach our accommodation fundraising goal.

The riders

Team Park Regis











Team KPMG



Team Friends and Family



Team KPMG (cont)



James Ure



Team Heart



Stephen Gow



James Russell

Bob Quirk



Adam Dodd

Team Victory

John Morris



Peter Riley

Ash McIntosh



Craig Edwards

Paul Commins



Harry Commins



Brian Patterson

Jordy Wright

Team Homicide





David Dunn Nigel Howard Want to know more about our riders?

Each of our riders are supporting us to reach our \$200,000 goal to fund accommodation for transplant families.

All donations over \$2 are taxdeductible, and as a volunteer organisation, every dollar you donate goes directly to help families.

Visit www.tourdetransplant.org.au to see riders individual stories and fundraising journeys.

More about Team Homicide...

Team Homicide will have a number of riders joining the peloton at different Tour stages - Christina Croxford, Peter Ferrie, Paul Quinton, Chris Westwood and Assistant Commissioner Tim Cartwright. Then on Sunday 30 March, other Homicide Squad Cycle Team members will join Tour de Transplant riders on their way to join us at the HLTTV Easter BBQ.

SPECIAL EVENT NOTICE HOMICIDE - AN INVESTIGATORS INSIGHT

What happens behind the scenes as police build their cases to bring criminals to trial? Gain unique insight from our guest speaker: Ron Iddles Tuesday 15th April 2014, 7pm for 7.30 start

Alexander Theatre, Building 7 Monash University Wellington Road, Clayton Melways ref: Map 70 F11, Map 475

Tickets \$30 per person including light refreshments ALL PROCEEDS KINDLY DONATED TO THE SECOND CHANCE ACCOMMODATION PROGRAM

Seating is limited so book early!

Tickets for this event can be purchased online at the website link: http://tinyurl.com/lgcggb2 All event enquiries to Elly Anderson on 0400 542 210 or ellyanderson@iinet.net.au



A silver milestone during DonateLife Week 2014

25 Years of Excellence from the Alfred Transplant Unit

A discussion with Jamie Hobson, Transplant Liaison Nurse Coordinator to mark the Alfred Transplant Unit's Silver Anniversary

On 27 February 1989, Professor Don Esmore performed the Alfred Transplant Unit's first heart transplant. Supported by a team including recently retired (September 2013) Transplant Co-ordinator Anne Griffiths, the team has continued to grow and achieve ground-breaking milestones including:

- Ranking as the sixth largest transplant unit in the world
- Responsible for the first lung transplant after circulatory death (Greg Snell/Bronwyn Levvey)
- Pioneers in bypass (ECMO) technology
- Nationally funded centre for paediatric lung transplants
- Performing an average of 90 life-saving transplants every year

Current Transplant Liaison Nurse Coordinator Jamie Hobson is proud to be part of a Transplant Unit recognised worldwide for these advancements, and more.

Jamie believes an ethos of 'If it can be done, it will be done" is a defining characteristic for the transplant unit, and while the history of the unit is an incredibly proud one, they have their eyes firmly on what the next 25 years may bring.

Read the rest of our interview with Jamie by visiting the 'news' tab on our website: www.hlttv. org.au Our jam-packed special 'Tour' edition simply didn't have the space for the 'full stories' - please make sure you visit our website to see the rest of what Jamie and Victoria had to say.

DonateLife Week 2014 - Q&A with Victoria Dale from DonateLife Victoria

DonateLife Week is Australia's national awareness week to promote organ and tissue donation.

This year it took place from Sunday February 23rd to Sunday 2nd March 2014. It's the perfect opportunity for everyone in Australia to sit down with their loved ones and 'have the chat' about their organ and tissue donation wishes.

Camille Condon caught up with Victoria Dale, a DonateLife Coordinator for DonateLife Victoria.

What is the role of the DonateLife Co-ordinators in the organ donation process?

The Organ Donor Co-ordinator (ODC) is responsible for providing additional information about the organ donation process to families of potential donors, obtaining formal legal consent and coordination of the process.

This includes taking blood samples for testing and cross matching, collecting medical and social history about the donor, referral of organs to the transplant units, and organising the donor surgery at the donor hospital.



This process can routinely take 24 hours, and during this time we continue to support the donor family, and provide ongoing support and education to the hospital staff.

We are present during the donation operation, and manage the legal documentation, packaging and transport of the organs and tissues.

After a donation case we contact the donor families to provide ongoing support and provide them with some de-identified information about how the recipients are recovering, so they have a sense of the gift that they have given.

Is there a coordinated approach across Australia, and what steps are being undertaken to improve the organ donation rate in Australia?

There have been major changes to the organ and transplantation sectors in Australia since 2007 with the most significant being the implementation of the national reform agenda and the establishment of the Australian Organ and Tissue Donation and Transplantation Authority (OTA) in 2009.

The OTA works with states and territories, clinicians and the community sector to deliver the Australian Government's national reform agenda to implement a world's best practice approach to organ and tissue donation for transplantation.

Read the rest of this fascinating interview with Victoria by visiting the 'news' tab on our website: www.hlttv.org.au

Tour finale and Easter BBQ



Join us for the annual HLTTV Easter BBQ on Sunday, March 30 2014 from 11.30am on Fawkner Park Lawn, opposite The Alfred.

> FREE food and drink for members.

We'd love to see all members and supporters on hand to welcome back our Tour de Transplant riders after their 1,100km odyssey.

The HLTTV Easter BBQ is a key event for all members and partners, but in 2014 it's even more special as we welcome the Tour de Transplant riders and their families as the riders finish the Tour.

Held in the beautiful surrounds

of Fawkner Park, this year's BBQ is truly something to look forward to.

All food and soft drinks are FREE for members, and events on the day will include one of our fantastic raffles, and some very special visitors for the kids. BYO shelter, chairs and rugs. We start at 11.30am on the Fawkner Park Lawn opposite the Alfred main entrance. If you are interested in sponsoring the event in any way, or providing raffle prizes, simply email events@hlttv.org.au