



# TRANSPLANT AUSTRALIA WA NEWSLETTER

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# **Chairperson's Report**



BY: Julie Edmonds

Hello TAWA Members and Supporters,

Welcome to a New Year of sharing experiences, supporting each other, enjoying social events, forging new

friendships, and engaging with the community to spread the word on organ donation.

2015 ended with a successful TAWA Christmas Party which everyone enjoyed. 2016 brings us many social opportunities in our State and the Australian Transplant Games in Sydney (Penrith) 24 September – 4 October.

In this Newsletter you will find information on the 2016 Brooke Tran. Sydney Transplant Games and the 2017 World Games in Spain ... start planning now! The next Sausage Sizzles are at Bunnings Subiaco on 9th April and 7<sup>th</sup> May, this day also raises funds and promotes community awareness. Wishing you

TAWA receive no funding other than fundraising or grant applications, we are volunteer based and welcome everyone to Committee meetings or as a volunteer in the rewarding community work we do.

Paul Turner's Mall Yarns are gaining member support and Paul is to be commended for his achievements in Community Engagement. Don't miss Paul's Community Engagement Corner in this Newsletter. Paul also co-ordinated the TAWA stand at the Hyde Park Community Fair on 6<sup>th</sup> March.

There is also the lawn bowls on 10<sup>th</sup> April and dragon boat racing on 1st May. Looking further into the future is the City to Surf in August, facilitated by Ken Truslove, Write to Your Donor Day in October, facilitated by Paul Turner, and the HBF Run in May facilitated by Brooke Tran.

Scholarship opportunities are now open for 2016, with a closing date for applications being 30<sup>th</sup> May. You can learn more about this opportunity in this Newsletter.

Wishing you all happiness and good health in 2016!



#### **In Memory**

In the past year we have lost two stalwarts of the TAWA team in Jill Coughran (left) and Audrey Wood (right).

Both were originally members of TA in NSW but on moving to WA they became members here and represented us at many Transplant Games. Double lung recipients, they demonstrated that extraordinary drive which enabled them to compete over and above any health issues that got in the way.

Jill, TAWA Treasurer from 2005 to 2010, would regularly rise from her hospital bed at the Games to return to the competition

Audrey would hurtle that small body of hers quite a distance in the long jump having detached herself momentarily from the oxygen cylinder in order to jump.

We remember and honour these brave women.





# The Australian Transplant Games 2016 24 Sept to 1 Oct, Western Sydney NSW

**REGISTER NOW** 

#### Are you coming to the Games this year?

The Australian Transplant Games are in Sydney this year and you can come to them whether you are a recipient, a donor family member, a living donor, a medical professional or a supporter. You can come whether you are a kid or an adult, a couch potato or an elite athlete. You can come to win or you can come to simply 'have a go'. They are a celebration of life you won't want to miss. Bring the family!

They are an inspirational event aimed at spreading the word about organ donation and they will be held in state of the art venues including Sydney's International Regatta Centre, Panther's World of Entertainment, Blacktown Swimming Pool, Penrith Golf Club, AMF Rooty Hill, Blacktown International Sports Centre and more. Our opening ceremony will be held at the beautiful Regatta Centre, home of water sports at the Sydney 2000 Olympics.

There will be events for recipients, donor family members, living donors and supporters and these events range from the more athletic ones through to chess and scrabble. Something for everyone so why not think about joining us.



# The World Transplant Games 2017 25 June to 2 July, Malaga SPAIN

Thinking about a trip to Europe? Why not time it to coincide with the World Transplant Games where recipients from around the world are united by the generosity of the gift of life. The World Transplant Games are the largest organ donor awareness event in the world.

If you are a recipient and you have competed in the Australian Transplant Games, you can compete in the World Transplant Games and you will find it is one of the most wonderful and exciting experiences you can have. These Games in Malaga will include all the usual sports with the addition of some extra cycling

events including a team cycling event, kayaking, darts

and a couple more new events.

Málaga is a port city on southern Spain's Costa del Sol, known for its famous citadels and hotels and resorts jutting up from the yellow sand beaches — and of course it's the birthplace of Picasso. The restored historic centre of the old city bustles with taverns and bistros.

Visit <a href="http://wtgmalaga2017.com/en/">http://wtgmalaga2017.com/en/</a>





# **Upcoming Events**

#### **LAWN BOWLS AFTERNOON**

#### Transplant Australia WA

Come along with family and friends on SUNDAY 10TH APRIL to Dalkeith Nedlands BOWLING CLUB

to enjoy an afternoon of fun in the sun. No experience necessary to join in the barefoot bowling session.

There will be a sausage sizzle to follow and the bar will be open from 4 pm.

DATE SUNDAY 10th April

VENUE Dalkeith Nedlands Bowling Club

ADDRESS 55 Jutland Parade, Dalkeith

TIME 2.30 pm

SHOES Flat soled shoes, barefeet or socks

COST \$10 Families \$5 Single Payable on the day.



ESSENTIAL for CATERING: RSVP to <a href="mailto:esthermdscott@hotmail.com">esthermdscott@hotmail.com</a> by Wednesday 8TH April with anticipated numbers. ALL AGES WELCOME!



#### **DRAGON BOAT RACING Try Out**

This year at the Australian Transplant Games in Penrith NSW there will be a dragon boat race between the competing states just prior to the Opening Ceremony. This will be a public event not a trophy event and will be a celebration of life.

However we always like to provide a bit of bite and demonstrate the West Australian fighting spirit so we are holding a "Try Out" day to provide some

familiarity with dragon boat racing for our members. This is your chance to have a go and you might decide you really like it and want to take it up for exercise and enjoyment.

Our hosts will be the COCKBURN DRAGONBOAT CLUB which operates out of East Fremantle Yacht Club and who have kindly offered to introduce us to the sport.

**VENUE** East Fremantle Yacht Club, Petra St, East Fremantle

DATE Sunday 1<sup>st</sup> May

TIME 9.45am for 10am start

CLOTHING When paddling we wear shorts & T's for guys. Women wear the same or sports/gym wear.

Thongs will be ok on feet.

SHOWERS Hot showers are available afterwards

Restaurant facilities are available at the Yacht Club for those who would like to stay for lunch but a club member will need to sign you in.

Now is your chance to have a go so don't miss this opportunity even if you won't be able to make the Games. We need to tell the club how many of us to expect so please let us know if you are coming as soon as possible.

RSVP to Marg Martin <u>martin.margie@gmail.com</u> or ring 0415 926 907





# **Upcoming Events**

## Next Sausage Sizzles – April 9th & Mother's Day

Last year we held two sausage sizzle days at Bunnings, Homebase, Salvado Road, Subiaco. They coincided closely with Mother's Day and Father's Day. While we toiled to raise funds for TAWA selling sausages in buns and drinks, we were also helping to raise community awareness of organ and tissue donation.

Paul comments on the September stall. "It was great to have Dean and the two Davids join us at the sizzle for the first time and take the tongs. After lunch, Elvis also helped adding a lively cabaret feel to the stall."

Our next sausage sizzles will be held at the same venue on **9**<sup>th</sup> **April** and **7**<sup>th</sup> **May** and helpers would be greatly appreciated.



If you are able to help please contact George Hobson at <a href="mailto:george@hobson.id.au">george@hobson.id.au</a> or 0429 617 377.

# Get that HBF JOIN US! run feeling! Sunday, 22 May 2016 This year, a TAW the Australian Tr

#### IOIN US! 12km RUN...4km WALK...

This year, a TAWA team has been created to kick start our training for the Australian Transplant Games and to raise money for the WA team at the Transplant Australian Games held later this year in Sydney. You can help make a difference by participating in the HBF Run for a Rea-

son 2016. If running or walking isn't your thing, you can donate just a few dollars. You are welcome to invite your friends and family to the team. The more the merrier and please share this page to help spread the word and promote organ donation awareness. Thank you in advance for your generosity and support, it means a lot.

Follow this direct link to register in the team;

https://www.registernow.com.au/secure/Register.aspx?E=19720&G=28666

Or follow this direct link to make a contribution:

https://hbfrun2016.everydayhero.com/au/brooke

And follow this link for more event information;

https://www.hbfrun.com.au/

#### CITY TO SURF 28th AUGUST

This year on August 28th there is a "DonateLife" team in the City to Surf Fun Run, funds for which go to the Active Foundation to help handicapped children. The team last year consisted of 49 people in total across the 4km, 12km and marathon categories. It was a very enjoyable day in good weather and it helped us blow out a few cobwebs and shed some winter comfort. More importantly it enables the promotion of the donation message across the event. Massive thanks to team captain, Ken Truslove who arranged the day jointly with DonateLife, Heart and Lung Foundation, and Liver Foundation.

All members are encouraged to participate and to invite friends/family to join the team – the larger the team, the more powerful the message. The cost is about \$45.





#### Interest



## **Transplant Australia Sports Committee**

Transplant Australia's Sports Committee is made up of representatives from each state who meet regularly (mainly via teleconference) to discuss the Australian Transplant Games, the World Transplant Games, and various other sporting programs run by Transplant Australia.

WA Representatives on this committee are Marg Martin and Julie Moloney (pictured left) backed up by Esther Scott when needed.

#### **Australian Donor Rates are on the rise**

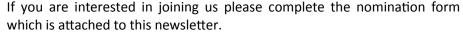


Did you know that Australia's donation and transplantation activity reached its highest levels in 2015.

See more at: http://www.donatelife.gov.au/2015-record-year-organ-and-tissue-donation-and-transplantation-australia-0#sthash.IRssuue0.dpuf

# **Appointment of Office Bearers - TAWA**

Every organisation needs new people involved in order to keep it vital and meeting the needs of its members. We are seeking members who would like to be involved with the committee in any capacity. Appointment of new office bearers will take place at our May meeting.





#### **Tablet Boxes**

If you have one of those large tablet boxes at home, the ones that are designed for Cyclosporin, and you no longer have a use for it, please contact Marg Martin at <a href="martin.margie@gmail.com">martin.margie@gmail.com</a> or ring <a href="martin.margie@gmail.com">0415 926 907</a>.

They can be hard to come by if you are not a new recipient.

PlusLife, formerly the Perth Bone and Tissue Bank, is a WA not-for-profit organisation dedicated to enhancing lives through the gift of bone and tissue donation.

Unless PlusLife get an urgent commitment of funding from the State Government for their new facilities ahead of this year's budget, they won't be able to help people like Harry and Jenni in the future.

View Harry and Jenni's stories on youtube to get an idea of the services provided by PlusLife.

https://www.youtube.com/watch?v=xx43lrWqik0&feature=youtu.be https://www.youtube.com/watch?v=eUVl8fT30sc&feature=youtu.be http://www.pluslife.org.au/





# **Community Engagement Corner**

BY: Paul Turner "Hello again members"

#### **Discussion and Advocacy**

Those who know me a little will know I am quiet and a poor public speaker. Perhaps I am not alone. The problem is solved by DonateLife, providing us with a talk and facts to follow when discussing donation. Armed with materials like the DonateLife presentation a brief talk on organ & tissue donation is not too hard.

#### http://temp.donatelife.gov.au/resources/guide-for-community-speakers

If public speaking is not your thing, but you know of an opportunity for a public speaker, please get in touch with me because there are some members who are experienced at it and happy to stand in. I am not particularly concerned with the quality of the presentation – I consider that a fairly brief and positive presentation is best – with the key being to point people to the Donor Register website or distributing the donor registration forms. Just our presence as recipients is invaluable and is our way or contributing to helping save the lives of others.

#### **Physical Presence**

I believe that community engagement is achieved by presence at community events. With the help of TA head office, Sydney, we have had some colourful banners made, which we can use to display at community events to fly the donation flag. Coupled with this presence is the distribution of registration forms where possible.

Events like Fun Runs involve us in light, happy and positive community activities, which can provide a positive tone to donation which, by its nature, is a deep and serious topic.

#### Digital Presence (Now I am getting out of my depth)

With the public becoming more computer literate and spending more time on them, the opportunity is there for us to be active in this area. Transplant Australia has a website (www.transplant.org.au) which is developing all the time. Each state has a page on that site, with the WA page being administered by Marg Martin - check it out and recommend it to others. DonateLife also has a wonderful website, full of information. Check that one out too and forward links to others, particularly the donor registration form.

Transplant Australia WA has its own Facebook page administered by our chairperson, Julie Edmonds. Please support us and contribute and post on that one to keep the friendly banter going. That's all for the moment. If anyone has any questions, discussion or information on community engagement generally, please contact me on 9387 375, 042 443 3073 or <a href="mailto:annepaulemma@bigpind.com.au">annepaulemma@bigpind.com.au</a>



#### **Annual Street Appeal Friday March 11th**

Many thanks to all those members who gave their time so willingly on Friday 11<sup>th</sup> March to help shake a bucket at our annual street appeal. It can be hard work carrying those buckets around when they are full of coins. Money raised at the Street Appeal enables us to meet the ordinary running costs of an organisation such as TAWA but equally important was their presence of members on the streets helping to raise awareness of organ donation in the city.

We would also like to thank the students from Perth Modern School (two of whom are pictured here with George Hobson) who joined us for a couple of hours in the morning and did a great and willing job collecting.



# **Community Engagement Corner**



BY: Paul Turner

Last October we held our **Write to Your Donor Day** to discuss with some newer recipients the process of writing to donor families. Privacy issues were discussed and some tips on when to write and things you can say. The aim is to encourage as many recipients as possible to send letters or cards of sympathy and gratitude to donor families. These letters or cards provide a little comfort during the grieving period and affirm the donor families' decision to donate. Donor family members have often indicated that they find themselves waiting to hear from recipients.

#### Winter Mall Yarns

One of our projects last year was holding stalls on some Saturdays in shopping centres promoting organ and tissue donation.

In August we were at **Mirrabooka Square** covering a wide open space and approaching shoppers. Thanks to Russell, David, Julie, Jennifer, Clarry, Carmel, Maureen and Brooke for your work on the day. Later in the same month we had a great site at **Mandurah Forum** and Les, Barb, Alice, Jo, Tracey, Dianne, Audrey and Helen did an excellent job in taking our message to the community.

In September, we held our final stall for the year at **Carousel Shopping Centre**, which went particularly well with much help provided by George, Pamela, Kylie, Pauline and Tom, Kelly and Mike, Anthony, Val, Beth, Carli, Marcus and Geoff. We were kept busy talking to people encouraging them to decide their donation wishes, and thanking those who have already registered.

The project has continued this year and, as always, all members are welcome to assist.



## **Tackers, Switzerland**

Imagine going to the Swiss Alps to ski and just have fun with 40 other organ transplanted children from around the globe? Eight year old Deakin Tran got to experience such an amazing trip in late January with **Tackers,** located in the small and boutique town of Anzere, Switzerland.

The children aged from six years old to sixteen, were cared for in the Chamonsairre by live-in camp counsellors, nurses and chefs. Their morning started off with 3-4 hours of skiing/snowboarding and then a whole range of activities from art and craft, swimming, karaoke, a disco and bonding sessions.

Deakin was assigned a room to share with a ten year old boy, Tom from New Zealand and another eight year old boy, Jelle from the Netherlands. Another Aussie boy, Bradley Stanley and his mum, Katie from Canberra also attended. Not only did the children form bonds, but so did the parents.

Thank you Liz Schick (founder of Tackers)

http://www.tackers.org/





#### For the Kids

BY: Katy Mandeno

organisation dedicated to supporting children, teenagers and adults with diagnosed Primary Immune too, and we were very excited to recently send Tom Deficiency (PID) disorders as well as liver, gastro, bone marrow and bowel transplant children.

There isn't an official 'transplant' organisation in New Zealand, so the Kids Foundation is the national charitable organisation families can turn to for help, to improve quality of life for the child their patient and families. The Kids Foundation / IDFNZ assist with everything from hospital stays, medical research, travel costs (both within New Zealand and overseas for specialist treatment) to a strong membership network to meet other families and special events for the children (Christmas parties etc). Members and their families

are assisted with a wide range of emotional, financial Transplant Games! and medical specialist support.

IDFNZ stands for the Immune Deficiency Foundation of New Zealand, and was first established in 1989 to

support New Zealand families struggling with chronic illness relating to Primary Immune Deficiency (PID), The Kids Foundation / IDFNZ is a non-profit which are often rare and very hard to diagnose or treat. Our family members now include transplant families Brown (pictured left) and his mum (Katy) to the Tackers Ski Camp in Switzerland.



While in Switzerland, Tom met up with two of Transplant Australia's members, Deakin Tran (from WA!) and Brad Stanley (from the ACT). The boys had an incredible week of skiiing, building snowmen, making new friends from around the world, partying generally loving life.

Tackers is an amazing example of the great things that happen when families can come together and share their experiences and stories. Lifelong connections were made, and we might even see Tom at the next Australian

For more information about transplant support in New Zealand, visit www.idfnz.org.nz or www.facebook.com/kidsfoundationnz



#### ARE YOUR KIDS STARTING WINTER SPORTS SOON?

Just a reminder to parents that your transplant child may be eligible for a Kidsport Voucher from your local government.

KidSport enables Western Australian children to participate in community sport and recreation, no matter their financial circumstances. Eligible youth aged 5–18 years can apply for financial assistance to contribute towards club fees of up to \$200.

Please go to the below link to download the form;

http://www.dsr.wa.gov.au/funding/individuals/ kidsport/information-for-parents

#### Anne Bradshaw Scholarship

Applications are open to children and youths, ages 25 years and under, for the 2016 TAWA Bradshaw Scholarship Scheme. If you would like to apply, or know of a TA member you believe would benefit from this Scholarship, please email Julie Edmonds

#### jedm6618@bigpond.net.au

Previous Scholarship recipients have used their funds to help pay for education costs, laptops, IT equipment, medication expenses and other items which have assisted in making their lives easier. Guidelines are available on request.

Closing date: May 30th





# **Past Events**

# 2015 Tree Planting and Thanksgiving Ceremony

The annual Tree Planting and Thanksgiving Ceremony was held at the Bendat Parent and Community Centre and Lake Monger on behalf of the Transplant Community. We heard personal stories from a DonateLife co-ordinator, a Respiratory Physician, the mother of a donor about her beautiful son and following his wish to be a donor, and very grateful words from a young lady, a cystic fibrosis lung recipient. This was followed with a prayer, the candle lighting exchange symbolising the passing of life, and the tree planting ceremony symbolising the growth of new

# DonateLife WA Honour Ceremony

# at City Beach on Sunday 6 March 2016

After more than 15 years at Lake Monger, the annual ceremony to honour organ and tissue donors and their families upped anchor and moved to its new site at City Beach on Sunday 6 March for a sunset ceremony.



# **TAWA Christmas Party**

On Sunday November 28th, TAWA had their Christmas Party on the Matilda Bay foreshore from around 11am. Lots of members, friends and families turned up to celebrate and join in on the festive season activities and BBQ. Thankfully the weather wasn't too hot but just right for some children to take a dip in the water.

Thank you to Esther for reserving for the gazebo for us and to all the lovely helpers that set up, prepared the food and cooked the BBQ. It was a delicious spread. The children also had a special visit from a Christmas fairy and an Elf. They entertained the children (and a few adults) for two hours of games, singing, dancing and a few special gifts.

Thank you to everyone that attended and helped!





#### **CONTACT US**

# Entertainment<sup>TM</sup> Books for the 2016 | 2017

TAWA is selling Entertainment Books again this year. Contact Sue Abbott if you wish to order a copy.

sabbott2010@live.co.uk

0438 904 294



Transplant Australia WA
PO BOX 347 FLOREAT WA 6014

www.transplant.org.au

If you are receiving this newsletter by post we no longer have a current email address for you. If you have a current email address please email

martin.margie@gmail.com

with the heading *Change of email address for TAWA* giving your name and new email address.

#### Next TAWA Meeting is May

Contact Marg Martin for details

#### martin.margie@gmail.com

Office Bearer elections will take place. All Welcome!



## **OFFICE BEARERS**

**Chair** Julie Edmonds jedm6618@bigpond.net.au

#### Secretary

Any volunteers?

**Junior Development Officer** Brooke Tran brooketran@hotmail.com

**Newsletter Editor** Brooke Tran brooketran@hotmail.com

**Treasurer** Esther Scott esthermdscott@hotmail.com

**Social Organiser** 

Any volunteers?

**Publicity** Kate Bone Kate.bone@bigpond.com

**Donor Family Delegate** Sandra Hampton 4161san@gmail.com

**Web Site & Membership Manager** Margaret Martin martin.margie@gmail.com

**Living Donor Delegate** Julie Moloney julemark@gmail.com

**Community Engagement** Paul Turner annepaulemma@bigpind.com.au

**TAWA History** George Hobson george@hobson.id.au

**TAWA Property** Glenda Rayment glendarayment@gmail.com

### DonateLife Week 2016

Sunday 31st July—Sunday 7th August Please keep this date in your calendar

#### **CONTACT LIST**

To help us communicate with other members we have a Contact List. This is a private list for members only and we ask members to treat it as such taking care to respect the contact details of others.

To have your name on the list, under privacy laws you must give your consent.

If you would like to be added to the list please contact Marg Martin at martin.margie@gmail.comThe current **Contact List** is attached.

