

the national charity for organ donation and transplantation



January 2022 - June 2023

**Members Update** 

## Our Vision

Committed to promoting organ donation and improving the quality of life of all Australians on their transplant journey.





## **Chair's** Report

**Transplant Australia emerges** from a demanding, yet rewarding, period. We are healthy and ready to tackle the next challenges to help our community 'make the most of life'.

This Review covers the period from January 2022 to June 2023, reminding us of lockdowns, Zoom meetings and extended isolation to avoid COVID-19.

For Transplant Australia it was a turbulent but deeply fulfilling time. Turbulent because we faced significant challenges in remaining operational through a period in which we were unable to undertake core activities such as the Transplant Games. Rewarding because our focus on helping our community through the pandemic through a range of webinars with leading experts was so deeply appreciated.

It was also a challenging time as Transplant Australia had been entrusted by the rest of the world to host the World Transplant Games in Perth in April 2023. Yet for a significant part of the lead-up it was uncertain whether restrictions would allow the Games to go ahead. It was not until nine months out from the Games - in July 2022, that we confirmed the Games would proceed.

The undertaking of a World Games, bringing together athletes, donor families, living donors, supporters, family members, stakeholders, funding agencies, sports facilities, special event services, volunteers,

media and promotion is not a light undertaking. Add to it the complexities of border closures, the high cost of international travel and lingering concerns of COVID.

I was fortunate to attend the Games throughout the week and many moments will remain with me for life. The parade across Matagarup Bridge and into Optus Stadium was something to be treasured. The joy on the faces of so many people reuniting from around the world was also something very special. To see recipients happily give their hardearned medals to others, such as donor families or those who had suffered reminded me of the goodness in humanity.

The Games is something very special and we should never take it for granted.

Equally it was pleasing to see Australia's rate of donation lift significantly in the three months following the marketing and media promotion of the Games. While it is always difficult to understand the cause and effect, swamping Australia with positive stories about donation and the success of transplantation can only be a good

Our staff deserve the thanks of our entire community for the commitment and energy to bring these Games to life. Our national team are committed and caring and can open doors for our community.

I would like to thank my fellow Board Members, especially Professor Richard Allen, who stepped down this year after a decade of service. Thank you also to the committees in our states and territories, volunteers and members who support us.

It is an exciting time for Transplant Australia and I am proud to be a part of it. Good times ahead.





## **CEO's** Report

The purpose of a Members' Review is to look back and report on performance over a period of time. In this review you will find reports on the key activities we have undertaken in the 18 months to June 2023.

These include the delivery of the World Transplant Games in Perth in April; rolling out Transplant Active through training camps and weekends across the country to help connect and motivate our community; advocating strongly for improvements to organ and tissue donation; and helping to support our community through the backend of the COVID pandemic with education and resources to keep them safe.

We sadly lost overnight the driving force behind many of our initiatives to help members - Matty Hempstalk, Matty, with his lived experience of kidney transplantation, was a great advocate for his community and helped shape our programs. His loss was felt deeply amongst the community and our staff – he had become such a great friend to all of us.

In the past there were two significant milestones when we had asked the community their views on Transplant Australia - first when I joined as CEO in 2007 and secondly when Matty joined as Membership Manager in 2017. In between of course there were other opportunities to undertake specific surveys and received important feedback on our direction.

In 2007, 47 per cent of the respondents rated the membership of Transplant Australia either valuable or extremely valuable. Ten years later that had grown to 55 per cent. This year's survey places that response at 61 per cent. It is only one factor, but it is pleasing that we are tracking well on providing value to our community.

We also asked what our priorities should be with 77 per cent of respondents ranking promoting organ and tissue donation and registration in their top 3. Supporting people along their transplant journey came in second at 66 per cent and 50 per cent of respondents believed advocacy to government to and health authorities was important.

The survey also showed the Transplant Games was not for everyone, however, even if you were not interested in the Games, there was universal recognition of the role it played in demonstrating the living proof of donation.

These results, coupled with feedback we have received from stakeholder engagement with key funding authorities, transplant professionals and recipients, will help pave the way forward post the World Transplant Games.

Our key pillars will still centre around advocacy; sport and physical activity; and education and support.

It is clear recipients need help along their journey and unfortunately traditional care models often provided through

transplant units and posttransplant follow up are becoming harder to reach, as staff take on more and more workload. Transplant Australia, in working with the profession, aims to build a suite of support services helping those waiting, recipients, living donors and carers through their

At the same time, we are looking to expand programs that can help lift donation rates. We don't have all the answers here. But we continue our support of the Organ & Tissue Authority to inform government of evidence-based, methods to improve donation.

Under our new plan everyone will have a role to play with increased sharing of the stories of our community and an advocacy network to help elevate our messages to decision-makers.

We hope you can help Transplant Australia as it sets to help everyone make the most of life.

Chris Thomas CEO





## World **Transplant** Games

The World Transplant Games are the pinnacle in transplant sport and Transplant Australia was proud to host the 2023 Games in Perth. This marked the third time the event was held in Australia, following previous Games in the Gold Coast in 2009 and Sydney in 1997. The Games took place from April 15 to 21 and featured 17 sports across 12 venues, drawing in participants from around the globe. The event showcased the remarkable achievements of transplant recipients, living donors, donor families, and their supporters, embodying the spirit of organ donation and transplantation.

A total of 1520 registered participants representing 45 countries came together to compete and celebrate life. In addition, 532 dedicated volunteers lent their support to the Games.

The event was more than just a week of competition; it encompassed a 12-month program of lead-up activities and events to create awareness of the importance of organ donation and transplantation and encourage more people to register to be an organ donor. The events included:

- The Games Ambassador Program and the Gift of Life Baton ceremony at Olympic House, in the presence of International Olympic Committee President Mr. Thomas Bach.
  - A six-month countdown celebration at Optus

Stadium, gathering participants and the community to build excitement.

- Federal and WA State Parliament launches, cohosted by the Parliamentary Friends of Organ Donation, with high-profile attendees including Assistant Minister for Health, the Hon. Ged Kearney, Parliamentary Friends Co-Chairs. Dr Anne Webster and Dr Mike Freelander, West Australian Premier Mark McGowan and Deputy Premier Roger Cook.



- The Gift of Life Baton Ride. where altruistic kidney donor Gordon Rutty and friends journeyed 4,600km across Australia on motorbikes to carry the baton from the Gold Coast to Perth.
- Nationwide pre-Games activities, including Transplant Active days and training camps, encouraging more transplant

- recipients to be more active and to develop and prepare the Australian team for the Games.
- A Western Australian community engagement program fostering organ donation awareness through community, hospitals and a public exhibition at the WA Museum - Boola Bardip.

The Games itself commenced with a spectacular march of 1,000 athletes across Matagarup Bridge into Optus Stadium, where the event was officially opened by International Olympic Committee Vice President John Coates and young kidney recipient Robbie Yates along with government

ministers, Transplant Australia representatives and Noongar elder Dr Richard Walley.

Over the following six days of competition, participants set new world records, achieved personal bests, and formed lasting friendships, encapsulating the essence of organ transplantation

and donation. Among the notable accomplishments were the establishment of 58 new Transplant Games World Records in athletics and 47 in swimming.

The Games included a range of special events that were an opportunity to recognise the special gift given by living donors and donor families but also a time come together as a community and celebrate, away from the sporting field. Special events included:

2 | 2023 Members Update

#### World Transplant Games - continued

- DonateLife Fun Run, which was run in conjunction with the 5km road race and saw over 630 people from around Perth join Games participants in an inclusive promotion of organ donation.
- The Service of Remembrance and Thanksgiving which was a moving and inspirational multifaith service celebrated at the beautiful St Georges Cathedral where donor families, living donors, recipients, medical professionals, and supporters all came together in celebration of the gift of life.
- Donor Beach Walk at City Beach where over 300 people joined together to enjoy a relaxed walk along the beach, sharing stories and recognising the incredible gift given by donor families and living donors.
- The display of the Australian Donor Family Quilts at the Perth Town Hall



A Cultural Night at the WA
 Museum – Boola Bardip where
 Games participants donned their
 cultural outfits, let their hair down
 and danced and sang the night
 away.

- Junior Activity Program
which included a range
of activities from a family
day meeting some Australian
native animals at Caversham
Wildlife Park to a special Kids
Night In involving pizza, games

and a movie!

The Games also featured several firsts, including the use of a Games App with 1800 downloads, live streaming of key events to engage the global transplant community, the inaugural Transplant Triathlon, and the creation of the enduring Gift of Life Baton symbol.

Australia fielded its largest team to date, with 342 registered participants, including 50 juniors.

The youngest athlete was fouryear-old liver recipient Anthony Schiller, and the oldest, eightytwo-year-old heart recipient Terry Donovan.

The Australian team earned an impressive 256 medals, including 106 gold medals, placing second in the overall medal tally. Of those, the junior athletes secured an impressive 53 medals. Whilst there were many amazing achievements, some of note include:

- Kate Clark winning the inaugural Women's Sprint Triathlon
- Michelle Daley was awarded Women's Athlete of the Games for her exceptional performance across swimming, athletics and cycling events.

- TA Board member Colin Liebmann was awarded the Greatest Gift Donor Family Award for performances in swimming and lawn bowls.

The Games ended with the Great Aussie BBQ and Closing Celebrations. As the sun set over the Indian Ocean, participants were treated to a wonderful BBQ with visits from some uniquely Australian wildlife and music.

Inside the HBF Stadium award winners were given the red-carpet treatment as we recognised outstanding athletes, donors and the newly-minted, Spirit of the Games Award. The Perth LOC handed the flag to Dresden, Germany before Federation President Chris Thomas formally retired from his role, handing the presidency to Swiss liver recipient, Liz Schick.

The Games were voted a resounding success and a testament to the power of transplantation, and the global community it unites. Transplant Australia is proud of its achievements

#### World Transplant Games - continued

in delivering a world-class event celebrating the gift of life. The Games have played a significant role in helping to normalise organ donation by allowing transplant recipients a voice to show what they have achieved with their transplant. They have provided and will continue to provide the opportunity to raise public

awareness about the importance of organ and tissue donation.



The Games generated over 780 media pieces in Australia and 733 internationally.

The livestream of the Opening Ceremony had over 10,000 views. 78% of participants rated the Perth Games as excellent or very good, placing it as one of the most successful Games of all time.

"As a parent, the growth of my teenager from when we first heard about the World Transplant Games, to his representing Australia and winning of three golds and one silver medal has just been astounding."

Alana Prince, Supporter

"We can see where the Olympic values and the values of the World Transplant Games Federation are really coming together. How they are becoming a reality. The words and the mission we share is to

Mr Thomas Bach

## Our Sincere Thanks

On behalf of Transplant Australia thank you to everyone who made the Games happen and thanks also to the Australian Team Management. From the volunteers, to sports coordinators, partners, medical volunteers, and then the Australian Team led by Margaret Hill and Julie Moloney, the effort was outstanding.

4 | 2023 Members Update | 5



## **Activity** Review

Transplant Australia's activities comprise three areas of focus in advocacy. sports and physical activity and support of our community:

Perth202

LEGACY PROJECT

#### **Advocacy**

Transplant Australia continued its strong advocacy to represent the transplant community over the 18 months. Highlights included:

- Providing responsible, informed and professional commentary to media enquiries and interviews
- Formally addressing the Western Australia Parliamentary Inquiry into Organ Donation. Transplant Australia was represented by CEO Chris Thomas, WA State Chair, Trov Scudds and Indigenous Donor Family Member, Rowena Alexander.
- Prepared submissions to both the WA Inquiry and the Victorian Parliamentary Inquiry into increasing donor registration rates.
- Matty Hempstalk represented Transplant Australia on the Organ & Tissue Authority's Transplant Liaison Reference Group and the Community Engagement Group. Representation on the Community Engagement Group is now with Transplant Australia Manager, Stakeholder Engagement, Jo O'Farrell.
- Professor Richard Allen represented Transplant Australia on the NSW Implementation Advisory Group for Increasing Organ Donation in NSW.
- Briefed the then Opposition Health Spokesman, Mark Butler, on Transplant Australia's position on donation and transplantation.
- Briefed the new Assistant Minister for Health, The Hon. Ged Kearney on Transplant Australia's position on donation and transplantation.

- Prepared and released a Greatest Gift Legacy Document mapping changes needed to our system of organ donation in Australia and released that in Federal Parliament in November.
- Worked with a coalition of charities representing immunecompromised people to put the case for greater public health measures to protect our community.
- Director Holly Tyrrell represented Transplant Australia on the Australian Sporting Alliance for People with a Disability.
- Worked with key politicians in Western Australia to form a Parliamentary Friends of Organ Donation. Its first official function World Transplant Games.



## **Sports and Physical Activity**

**Activity** Review - continued

Our Sports and Physical Activity Programs were presented through the staging of the World Transplant Games (reported elsewhere) and the rollout of Transplant Active across Australia.

Transplant Australia was awarded a Participation Grant in 2022 from the Australian Sports Commission for its Transplant Active Program.

Transplant Australia had identified that a significant barrier to the participation in physical activity for patients pre- or post-transplant was fear of injury or damage to the at-risk organ. This fear had been significantly exaggerated due to COVID, as many in the transplant community are immuno-compromised and have had, and will continue to have, an extended period of lockdown. regardless of public vaccination rates.

Transplant Active focused its deliverables on encouraging and facilitating safe forms of physical activity and well-being education to address this significant barrier.

The program was supported by Julie Scudds, as well as Matty Hempstalk and others.

The program achieved the following key outcomes:

- Just on 2,000 people participated in the program.
- There were 167 sessions delivered.
- A total of 25 events over 12 different locations throughout Qld, NSW. Tasmania. Victoria and WA.
- 233 people participated in the new First Steps Challenge.
- A value-add involved marketing students from the University of NSW undertaking 2 projects to build a proposed physical activity intervention program to get transplant recipients moving.

- Pilates sessions were held online throughout the year and were much appreciated by those in lockdown.
- Other physical activities included walking, cycling, swimming, pétanque, volleyball, darts, tennis, badminton, lawn bowls, ten pin bowling, table tennis, squash, golf, triathlon, and basketball.
- Sessions on strength & conditioning, and sports psychology were also valued.

A key part of the program was the conduct of the First Steps Challenge which was designed to be held over a month to encourage transplant recipients and their families to engage in a month of challenges to improve their physical and mental well-being. A total of 233 people enrolled in this program. It was conducted on the Move Spring App.

Transplant Australia continues to represent it's members on the world stage. Chris Thomas stepped down from the presidency of the World Transplant Games Federation in April 2023 and Kate Clark was appointed as a Trustee. Marg Martin continues as our country representative to the



#### **Activity** Review - continued

## **Education** and **Support**

Our Education and Support activities provide important information for our recipient community while also providing social connection and inclusion.

Transplant Australia continued its COVID-related webinars early in 2022 to help our community through the pandemic. These included a webinar in May 2022 with 404 participants and another in November with 161 participants.

In June 2023 Transplant Australia sponsored a patient forum as part of the Transplantation Society of Australia & New Zealand Annual Scientific Meeting. Kidney recipient, Emmy O'Neill, was invited to speak about her experience in preparing and training for the World Transplant Games.

Prof. Richard Allen presented a poster at the meeting highlighting the medical services at the World Transplant Games.

Transplant Australia worked with Dr Rob Carroll to achieve a grant from the Sony Foundation to conduct clinics for young adults transitioning into the adult transplant setting. These clinics were hampered by the pandemic but will ramp up in the second half of the 2023.

The State Committees engaged in a range of activities that covered both support and physical activity. Highlights included:

#### NSW

- July 2022 Ten Pin Bowling at Rutherford Newcastle
- October 2022 Lawn Bowls Weekend at North Haven
- Significant financial support for its team to the World Transplant Games

#### **QUEENSLAND**

- Walks, Lawn Bowls, Putt Putt and Dayboro Day Walk

#### **WESTERN AUSTRALIA**

- Training camps and weekends across the State
- Involvement in Busselton Jetty Swim and Busselton Triathlon
- TAWA Yallingup Getaway
- Art of Giving Exhibition to raise funds for the Western Australian Team
- Xmas party
- Teens & Kids Camp
- Uniform presentation for World Transplant Games



- Members educational meetings



### **Activity** Review - continued

### Fundraising and Awareness

Transplant Australia supports awareness initiatives throughout the year including DonateLife Week, Thank You Day, Jersey Day and Saffron Day with social marketing and communications.

From taco nights to triathlons, our community find many other ways to help to raise awareness of organ and tissue donation. Many also fundraise to support Transplant Australia's awareness initiatives and we thank everyone who has advocated or fundraised for the cause.

Among these champions, some members undertook significant fundraising activities including Gordon Rutty who continued his Walk to End the Wait and Orange Ball on the Gold Coast; and Brett & Jodie Barton who established the Second Chance Charity Classic Golf Day at Queanbeyan to support Transplant Australia and the North Foundation.

## New Transplant Australia **Life Members**

Congratulations to Margaret Martin, Gordon Rutty, and Bernie & Nerida Morellini on being named Life Members of Transplant Australia, awarded at the Australian Team Dinner at the World Transplant Games.





8 | 2023 Members Update | 9



A message from the Chair of the Australian Sports Commission

- Josephine Sukkar AM

Sport has a place for everyone and delivers results that make Australia proud.

As we progress through this defining era in Australian sport, the Australian Sports Commission (ASC) is clear in our vision to lead and support the sector.

Our role is to provide opportunities for all communities to be involved in sport, while growing elite success and representation, inspiring future generations.

As the Australian Government agency responsible for supporting and investing in sport at all levels, we strive to increase involvement in sport and enable continued international sporting success.

We do this through leadership and development of a cohesive and effective sports sector, targeted financial support and the operation of the Australian Institute of Sport (AIS).

We play a unique role in the sport ecosystem and tackle the big challenges and opportunities with and for the sector.

We're proud to do so and through our vision, we aim to bring out the best in everyone involved in sport as we establish Australia as the world's best sporting nation.

Collectively, we've already made huge strides to set Australian sport up for success.

Australia's High Performance 2032+ Sport Strategy is an

industry-wide approach to harness our collective strengths, talent and resources.

The strategy has a strong focus on Winning Well – balancing success and wellbeing and acknowledging that how we win is just as important as when we win.

Working hand in hand with this is the codesigned National Sport Participation Strategy which will transform the way participation is connected, delivered and supported in Australia.

The strategy will be the first of its kind in Australia and I'm looking forward to seeing the positive impact it has on the sector.

The sporting strategies, programs and facilities we deliver now have the capacity to shape Australia's long-term prosperity, well beyond sporting boundaries.

This is a defining era for Australian sport. We are well into the Green and Gold decade to Brisbane 2032, and we are focused on building sustainable success for decades to come.

Meanwhile, it has been wonderful to see continued demand from sports to use the AIS facilities in Canberra to prepare for major events, at home and abroad.

As the national home of sport, we are proud of the role we play in supporting athletes, coaches and high performance staff to reach their potential and I look forward to seeing many of our athletes shine at the upcoming Paris 2024 Olympic and Paralympic Games and Milano Cortina 2026 Olympic and Paralympic Winter Games.

On behalf of the ASC, thank you to everyone who contributes to the sector as we work collectively to ensure every Australian sees a place for themselves in sport.

Josephine Sukkar AM

## Our Sporting Connections

Transplant Australia is a proudly recognised as a National Sporting Organisation with a Disability by the Australian Sports Commission, and one of nine members of the Australian Sporting Alliance for People with a Disability.



AUSTRALIAN SPORTING AL FOR PEOPLE WITH A DISAB

## **ASAPD Yearly Review**

## - Overview Report 2022 -2023

Our vision is for 'all Australians to have an opportunity to engage in sport and physical activity in a welcoming and inclusive environment'.

Our focus is to 'collaborate, advocate and facilitate inclusive sport and physical activity for Australians with a disability'.

Three workshops in 2017, 2018 and 2019 coordinated by the Australian Sports Commission was the impetus for the Australian Sports Alliance for People with a Disability (ASAPD) oversight committee to be formed, which then culminated in the formation of the ASAPD legal entity, in December 2022.

The ASAPD is a representative body supporting the Australian National Sporting Organisations for Disability (NSOD). Over the last three years there have been many successful outcomes, however, a key development is the growing awareness of the brand and the benefits provided to the NSODs. The one voice strategy has highlighted efficiencies and respect for the vision that all Australians have an opportunity to engage in sport and physical activity in a welcoming and inclusive environment.

The new entity is led by an independent chair who is supported by eight other directors who have been recommended and appointed by the NSODs. The constitution has been approved and lodged with ASIC and

subsequently recognised by the ACNC gaining charitable and PBI status.

The ASAPD has formalised its 2023 – 2027 Strategic Plan that highlights the following key focus areas:

Be the representative alliance for all people who have a disability, impairment, or limitation to enable them to fully participate in sport and physical activity in Australia.

Lead with a unified approach, which aims to build active enriched lives through a welcoming sporting and physical sector environment based on social inclusion principles.

Advocate, educate, inform, support, and build the capacity of the wider sporting sector to be inclusive for all people who have a disability, impairment, or limitation.

Foster relationships with governments and other key stakeholders to support the accessibility of sport and physical activity sector.

Ensure the ASAPD has a sustainable governance and management structure which supports its vision and mission.

Provide a central information platform(s) which promotes and shares key information on being more accessible and inclusive.

The ASAPD focus is driven by four key pillars:

Collectively achieve greater policy and funding outcomes

with Governments via advocacy, liaison, consistent communication, relationship development and sharing of expertise and knowledge. Such work will also occur with the sporting and physical activity sectors.

Improve the effectiveness of the sector by sharing resources and working in a collaborative and efficient way.

Build and expand awareness of the ASAPD purpose, facilitating exposure for the NSOD's by telling our collective story.

By driving a modern sports engagement theme develop and build projects that will enhance the reach, message, and improve the efficiencies and output of the ASAPD and its members. Create a Sport Information Portal and develop a collective data collection and design framework that can be used in applying for grants directly or indirectly with educational organisations.

With strategic and marketing plans, website, legal entity, and a social media program in place together with a brand that is gaining awareness and attention, we can set our sights on becoming the 'go-to authority in Australia for information relating to inclusive sports for those with a disability, impairment, or limitation.'

John Croll
Chair
Australian Sporting Alliance for
People with a Disability

10 | 2023 Members Update | 11

This Members Report should be read in conjunction with the 2022 Financial Statements available at:

transplant.org.au/annual-report-agm

# transplant ustralia

the national charity for organ donation and transplantation



Transplant Australia Ltd National Office



p. (02) 9922 5400

Freecall: 1800 827 757

e. contactus@transplant.org.au

w. www.transplant.org.au