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KIDNEY SUPPORT NETWORK
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QLD 4741

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KSN NEWSLETTER

Please be advised we are only producing newsletters three time a year.



In Loving Memory Of

Glennis Lowe	(Mackay)
Bevin Saron	(Mackay)
Rod Etherington	(Mackay)
Mike Jones	(Mackay)
Elizabeth Klausburger	(North Brisbane)

Supporting Kidney Patients for over 40 years

Reports From

The President

As I write, it is Volunteers Week and it would be remiss of me not to mention the ongoing wonderful work and contributions of our many volunteers across the state. From our drivers to our Op shop crews to our hospital visitors and support groups, we thank you for the time and energy that you put into providing services to people who are impacted by renal problems.

Unfortunately, I have to advise that our President of 5 years Andrew (Andy) Bull has had to resign due to work commitments. It's understandable that he needs to spend more time with his family. We would like to take the time to say a big thank you to Andy for all his hard work and generosity that he has provided over last several years.

At this time, I have taken on the role of temporary President to see KSN through until the AGM late in the year. My name is Trevor Waldron, and I have been a past President of KSN for a period of two years. Also, have been volunteering for KSN in numerous positions from a Driver, Transport Coordinator and Guest Speaker since 2012.

KSN is looking for Volunteer Committee members and especially a President,

KSN management committee Inc is searching for interested people to join our committee that oversees the operation and delivery of services to people with chronic kidney disease. Hopefully, new members may come from different centres across Qld.

Key Attributes for Committee Members

1. Ability to work with other volunteer committee members
2. People who are impacted by renal health concerns
3. Board, committee, or governance experience
4. Previous experience in business or health or legal or Not for Profit Organisations (not essential)
5. Monthly Meetings (usually virtual)

If you think you could be this person, please phone Liza Williams (Secretary) on 0428 877 028 or email secretary@ksn.org.au for further information.

At this stage KSN is developing priorities for the next financial year, if you have any thoughts on how we can improve or extend our support or services please contact Liza Williams in the first instance.

Thanks again to our volunteers.

Trevor Waldron

President

CKD rarely occurs in isolation and frequently occurs alongside **diabetes** and **cardiovascular disease**.

29% of Australian adults are affected by **one or more** of CKD, Diabetes and CVD.

The most **disadvantaged Australians** experience a disproportionate burden of CKD, diabetes and cardiovascular disease and a **higher rate** of comorbidity of these conditions.

Over **one-third** of **Aboriginal and Torres Strait Islander peoples** have one or more of CKD, diabetes or cardiovascular disease. These conditions occur at a **younger** age and progress **faster** than in non-indigenous individuals.

1 in 3 hospitalisations involve diabetes, cardiovascular disease and/or CKD (including dialysis).

Psychosocial factors – **depression, quality of life, cognitive impairment** – have complex and multidirectional associations with CKD, diabetes and cardiovascular disease.

Depression is highly prevalent in persons with CKD, diabetes and cardiovascular disease.

KSN would like to thank all our past and present Volunteers who have worked over the years. Our appreciation can not be expressed enough when I say thank you for a job well done. KSN has volunteers that also go out of their way to make our Clients daily life a little bit easier even if just listening or providing a hand foot massage or opening the car doors making them feel special. Well done to all KSN volunteers.



The Operations Manager

Hello Everyone

Well, it has been a slow start to the year, but we are still operating which is good news for everyone and we hope you all had lovely break at Easter. I would like to thank our Volunteers for working through our Covid Lockdown down period so we could still transport our clients in the Mackay and Sunshine Coast region.



KSN is pleased to announce that Queensland Central Support Group is now meeting again on a regular basis and would like to announce the upcoming meeting dates. Meeting will be held at 39 Goodoon Street Central Gladstone starting from 9.30 am on the 14th of May 9th July and 17th September for any further information please contact Pat Howard on

(07)4979 1752

Kidney Health Week was celebrated throughout all the KSN stores for the week of 17th March.

Everyone was delighted with all the fantastic flyers and brochures promoting Kidney disease Awareness.



Smiles were had all round as the Evans family sent their day at Sea World

Mackay Support group has started back also and will commence their meetings 7th June at the Jubilee Community Centre. We will be holding the meetings first Monday of each month.

Contact Bekk for more information on **0423 964 397**.

Mackay Branch

Our Organisation will be celebrating our 40th Anniversary of KSN by holding a Golf Charity Day and Nissan have been kind enough to donate a Vehicle valued to \$40 000 when you get a hole in one. Harris Pest Control have also been generous by donating \$2000 towards the advertising through Channel Seven who is also one of our Sponsors.

Please accept my gratitude to everyone who has Sponsored KSN, and we would like to invite the whole community to join in our great day out on the 28th of August 2021. Please contact Bekk Murray on 0423 964 397 for any further information.



Kidney Support Network Inc.
40th Anniversary Charity Golf Day
Saturday 28th August 2021
6 am Start
Sarina Golf Club

\$40 pp - 1 entry to the charity golf day
1 x Breakfast Burger & 1 x Burger at presentation
4 person Ambrose teams
Golf carts will be auctioned pre- tee off.
Raffles/ prizes to be won on the day.

Chance to WIN A CAR valued at \$40,000

When you get a hole in one on the 16th Hole

To book a team please call 0423 964 397 or 0428 877 028.



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Magpies Sporting Club



All Welcome to Attend

We have a range of stock still available for purchase, KSN wrist bands and a KSN Bear

Item	Members	Non-Members	
KSN Wrist Bands	\$5.00	\$7.00	Postage included
KSN Bear	\$25.00	\$25.00	Plus, Postage
PD Belts	\$14.00	\$23.00	Limited Stock Postage Included



Redcliffe Op Shop, Northern Brisbane.

I hope you all had an amazing Christmas & Happy New Year. Ours was undeniably better than our last one. As some of you may know our shop was flooded out on the 15th of December 2019 by a little storm which may have only lasted 30 minutes but closed us for 3 months. The amount of rain was so heavy that our roof & gutters could not handle it so in it came, our walls looked like water features & so were our lights & ceiling fans.

We have had the most amazing donations of late, our Landlords father recently passed away & his family kindly donated his priceless Bric-a-brac that you will only see once in a lifetime.

I also want to thank Michael for his tireless work picking up donations and big Thanks to the TOUMPAS Family.

Our valued Op Shoppers, thank you for you continued support & constant praise of our great little shop, with 5 Op Shops in our street we do extremely well & of course we would not be able to do without our volunteers, we do not have many but the ones we have are hardworking & really been an extension of our family. There is one exceptional volunteer who has been here from the beginning, she is my right hand & will always stay behind after hours" many times" to help organize when we have been inundated with donations, also she has a calming influence on every one of us & more importantly rocks up with good Aldi biscuits for morning tea to share with all of course, Thanks Sal you are one in a million.

If anyone is interested in volunteering please ask at the counter & we can get the paperwork underway. We do have a lot of fun, but we also work hard to maintain a Full, Clean Shop. Again, thank you to our Volunteers & customers for your continued support, everyone be Happy & Stay Safe.

World Transplant Games to take centre stage in Australia

By [Matty Hempstalk](#) January 3, 2021

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The World Transplant Games Federation (WTGF) today formally announced that Perth, Australia, would host the 23rd World Transplant Games in April, 2023.

The announcement coincided with the formal announcement by the Australian Government's Minister for Sport, Senator Richard Colbeck. Minister Colbeck confirmed that the Australian Government would provide \$600,000 to help Transplant Australia to host the Games. WTGF President and CEO of Transplant Australia, Chris Thomas, thanked the Australian Government for its commitment to helping to bring the world's largest awareness event for the gift of life to Australia.

"Senator Colbeck and the Minister responsible for organ and tissue donation, The Hon. Minister Mark Coulton, are strong supporters of Transplant Australia's mission to promote donation and help recipients lead a full and active life," Mr Thomas said.

The World Transplant Games will be staged in Perth from April 15 to 21, 2023. It will bring up to 3,000 transplant athletes, their families and supporters together for a week celebrating the ultimate gift – the gift of life.

Mr Thomas said Perth would be an attractive host city with its climate, modern sporting facilities and excellent health care services.

"Transplant recipients with their lowered immune status have taken lockdown from COVID-19 extremely seriously. We know these special athletes are yearning to get out on to the sporting field again. Hosting the Games in Perth will ensure that's done with their safety and health as the first priority," Mr Thomas said.

"We know everyone around the world are waiting anxiously for the success of the coronavirus vaccines. Recipients are no different. We are confident that we will have successfully navigated through this pandemic and, by 2023, recipients will be able to travel to Perth with confidence."

The Games, usually held every two years, will be the first since Newcastle, England, hosted the Games in 2019. Houston, Texas, was due to host the 2021 edition but withdrew because of the pandemic.

The WTGF Board of Trustees in August last year (2020) voted unanimously to award the Games to Perth. The WTGF and Transplant Australia have waited until the look was more promising before making the announcement.

The Games are open to those who have received, heart, lung, liver, kidney, pancreas, stem cells and bone marrow transplants.

They were first staged in Portsmouth, England in 1978 and have grown into the largest single event for donation and transplantation across the world.

While the Games is the flagship for the WTGF, it also undertakes several other wellbeing programs, including Fit for Life!, Refit for Life and the extremely successful Billion Steps Challenge.

The Games have been held on the continents of Europe, North America, South America, Asia, Africa and Australia. This will be the third time the Games have been staged in Australia with previous Games in Sydney in 1997 and the Gold Coast in 2009.

The Commonwealth Department of Sport and the Commonwealth Organ & Tissue Authority are two major sponsors already locked in. In 2021 other sponsors will be announced.

About the WTGF: The WTGF exists to promote organ donation and support transplant recipients around the world. It has more than 70 member countries and is recognized by the International Olympic Committee as a Multi-Sports Organisation. It is also an Associate Member of the Global Association for International Sporting Federations.

About Transplant Australia: Transplant Australia is the national charity for organ donation and transplantation, is a DonateLife Partner and is recognized by Sport Australia as a National Sporting Organisation with a Disability.

About the World Transplant Games: The Games are held every two years and have two objectives – to promote organ donation and the need for communities to commit to saving others – and to encourage transplant recipients to lead active and healthy lives.

[Minister Colbeck media release](#)

Further information:

WTGF:

kim.renyard@wtgf.org

Transplant Australia:

chris.thomas@transplant.org.au



Changes to Australian Deceased Donor Kidney Allocation



Kidney Allocation in Australia

The current deceased donor kidney allocation algorithm is a tiered national and state points-based system that has been in place since 1992. It is primarily based on immunological matching, sensitisation*, duration of dialysis, paediatric status and state balances. Eligible transplant candidates are listed on the national waitlist and matching system OrganMatch and are allocated donated kidneys using the algorithm.

At the national level, priority is given to patients with an excellent immunologic match, and those who are highly sensitised. If there is no national-level match, the process moves to a state-based allocation, according to immunological match and time on dialysis.

Review of Kidney Allocation

The TSANZ Renal Transplant Advisory Committee (RTAC) and the OrganMatch Renal Allocation Working Group (RAWG), in consultation with key clinical and community stakeholders, undertook a review of the algorithm. The focus areas to improve patient outcomes and deliver a more equitable system were:

- i **Improve access to transplant for highly sensitised patients**, who are otherwise very hard to match
- ii **Utility of deceased donor kidneys**, through survival-matching[†] of the recipient and donor kidney
- iii **Improve immunological matches for younger patients** to reduce sensitisation, as this group is more likely to need a second or subsequent transplant because in many cases they outlive their original transplant.

Kidney Algorithm version 2: Modelling and Implementation

The Kidney Algorithm v2 (KA_v2) was developed through an iterative process of consultation, modelling studies and simulation testing in OrganMatch. The revised algorithm results in improvements in each of the three focus areas.

- i The highly sensitised and very highly sensitised patients have increased access to an immunologically matched kidney if it becomes available.
- ii Introduction of the concept of survival-matching to improve utility of donated kidneys for maximum benefit.
- iii Younger patients are preferentially offered better immunologically matched kidneys to improve outcomes and decrease the risk of sensitisation, and therefore improve the chances of successful re-transplant if required.

The simulation outcomes and algorithm changes were endorsed by the OrganMatch Strategic Governance Committee. KA_v2 will be implemented in OrganMatch on 4 May 2021.

Next steps

The KA_v2 outcomes will be closely monitored and evaluated to ensure optimal results for our patients. Further enhancements are planned to continue to improve the deceased donor kidney allocation process.

For more detailed clinical information please refer to the TSANZ clinical guidelines link [here](#), which will be updated from the commencement of KA_v2.

*Sensitised patients: have high levels of antibodies, often because their immune systems have been previously exposed to foreign cells or tissues through, blood transfusion, foetus/ pregnancy or previous transplants. They are more likely to react against further exposure to foreign tissue (such as a donated kidney). It is therefore harder and often takes a lot longer to find a compatible deceased donor match.

†Survival-matching: Involves allocating deceased donor kidneys based on an assessment of how long a particular donated kidney is likely to last and matching that information with waitlisted candidates with similar estimated post-transplant survival.

COMMUNITY CHEST FOR KSN MEMBERS

HELP WITH YOUR TREATMENT TRAVEL EXPENSES

KSN has set aside a small pool of funding to enable us to now offer all current members (as of 1 October 2020) financial assistance towards their accommodation costs and 'out of pocket expenses' when travelling in excess of 25 kilometers to obtain medical treatment for any renal condition.

KSN will now -

- Pay a maximum \$100 per night towards your hotel accommodation expenses for a maximum of four nights per annum whether or not the four nights are taken consecutively.
- OR
- Pay a maximum of \$30 per day for a maximum of four days towards 'out of pocket' expenses during your stay if you did not incur accommodation expenses.

To be eligible for assistance with accommodation expenses, KSN members must provide us with –

- a written request for financial assistance (preferably by email at least two weeks prior to the commencement of the travel – or three weeks prior to travel if notifying us by post)
- a copy of your specialist appointment.

If financial assistance for accommodation is approved, you must subsequently provide us with a copy of the receipt for your hotel accommodation.

Or, if the financial assistance is just for your out-of-pocket expenses during any overnight stay, you must subsequently provide us with evidence of the length of the stay.

If you need any further assistance or have any other query regarding this funding please don't hesitate to contact Liza Williams, KSN Operations Manager on:

Mobile: 0428 877 028

or Email: operationsmanager@ksn.org.au or

Postal:

PO Box 6657 West Mackay 4740

Congratulations

KSN would like to acknowledge the following volunteers for their hard work and efforts year after year. Thank you for all for your motivation and encouragement given throughout the years. May you continue to inspire us for many years to come!

Name	Years' Service	Name	Years' Service
Elizabeth Williams	11	Denis Phillips	10
Jennifer Ann Scott	10	Samantha Lee Scott	10
Michael (Mick) Dawson	9	Trevor Waldron	9
Ray Bowers	6		

Supportive Care

If you have kidney failure you can decide to let nature take its course. Your life may be shorter, but your quality of life may be better. Your doctor can advise what the outcome is likely to be for you if you choose supportive care.

Simple Treatment

Choosing supportive care means you are not having dialysis or a kidney transplant. Some people choose this option after a time on dialysis, or they may choose not to start dialysis.



Advance Care Planning

This is the time to plan your priorities at this important stage of life. You can appoint a guardian, plan your future care, and consider where and how you would like to die.

Medications

You are likely to take the same medications as those who choose dialysis

These might include medications to control blood pressure reduce phosphate and improve anaemia.



Diet and Fluids

You will feel better if you choose a balanced and healthy diet. You may have to restrict your potassium and fluid intake.

Dietitians can provide specific advice.



Doctors Visits

You will visit your local doctor or kidney specialist regularly for check-ups.

You may also be referred to the palliative care team for specialised symptom control at home support.



