

your **KIDNEY** CONNECTION

MAGAZINE Autumn 2023



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CEO'S WELCOME

As we dive headfirst into 2023, I wanted to take a moment and welcome you all back and share some exciting updates.

Kidney Health Australia has taken up the challenge of being a voice of the community to the Australian Parliament. We launched a transformation report: *'Changing the chronic kidney disease landscape: The economic benefits of early detection and treatment'*. Our intention is to drive government investment in early detection and management of Chronic Kidney Disease and increase research funding. We are excited to see the impact it will have for kidney health in years to come.

Our Kids and Youth Program is back in full force, with plenty of new events planned. We are humbled to announce that the QLD, VIC and WA events were booked out, and we encourage families to register for the remaining events to avoid disappointment. Kidney Kids Camp is also back after a three-year hiatus, providing a wonderful opportunity for young people facing similar challenges to come together, switch off and have fun.

Thank you for your continued support of Kidney Health Australia, and we wish you all a happy 2023.



The Big Red Kidney Bus is another highlight, with locations now locked in for 2023. This renal-unit on wheels provides a much-needed break for those on dialysis and their loved ones across popular holiday destinations. With a 98% recommendation rate from previous users, we encourage you to book your spot and don't hold off any longer on that long-awaited holiday.

In addition, we are delighted to announce that over the next 18 months, we will be implementing our new pilot program, a Bus for the Gold Coast! In partnership with the Queensland Government and Gold Coast University Hospital, Kidney Health Australia will be bringing a much-awaited Bus to Queensland. In order for this initiative to continue beyond the initial 18-month period, we will require additional support from our generous donors. We look forward to seeing the positive impact this will have on our community as we know many have asked for a Bus in Queensland.

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KH4L BETTER KIDNEY HEALTH 4 EVERYONE

Kidney Health Australia is embarking on an exciting pilot program this year called Kidney Health 4 Life, to offer tailored and **holistic support for people living with kidney disease and their carers**. The program will then be assessed to determine the impact and understand how Kidney Health Australia might be able to provide this support ongoing.

Research facilitated by Kidney Health Australia last year with the support of research agency Atlantis Health identified key themes for people living with kidney disease and their carers, such as lack of knowledge about the kidney disease journey, loss of control over individual health, isolation felt by patients and carers, as well as the need for mental health and peer support.

The pilot program will run this year and recruitment for participants will be conducted from May. Keep your eyes peeled for more information via email and social media.

A lifetime of LOVE

To welcome a child into the world is one of life's greatest joys - but joy can quickly turn to heartache when your precious baby is diagnosed with a chronic illness.

Boston was just months old when he was diagnosed with Congenital Nephrotic Syndrome, a kidney condition that leads to childhood kidney failure. He was not even 12 months old when he had both of his kidneys removed - devastating his family.

Despite Boston's tough start to life, his Baba (great grandmother), Diane, says his strength and courage is what stands out most.

Your gifts can help fund much needed services to help ease the physical, emotional and financial burden for more families like Bostons living with kidney disease.

Did you know?

1 in 6 hospitalisations in Australia are kidney related. That's why we're working towards detecting kidney disease earlier, helping Aussies stay out of hospital and live their best lives.



“ Boston has grown up with this condition and although being hooked up to a machine every night to stay alive must be frustrating - he takes it in his stride. What an amazing little person he is!

Boston is surrounded by so much love from our entire family, however the ramifications of this medical condition are felt by everyone. The financial impact is enormous and the physical and emotional impact is immeasurable. ”

Diane says

Kidneys GO TO CANBERRA!

On **World Kidney Day** 9th March, Kidney Health Australia, our community ambassadors and key stakeholders went to Parliament House in Canberra to put early detection of kidney disease on the agenda of our politicians.

The event gave everyone - including politicians and their staff - a chance to get their kidneys checked for free, with doctors, nurses and pathologists on site.

Most importantly, Ministers were invited to a launch of the Deloitte Access Economics report, titled *'Changing the chronic kidney disease landscape: The economic benefits of early detection and treatment'*.

The ground-breaking report outlines the need for early detection to reduce the economic, social and human impact of late-stage treatment. It was found that for every \$1 invested in early detection, \$45 can be saved. This is a serious incentive for investing in early detection and treatment of kidney disease now, and Kidney Health Australia will be actively advocating for these changes in the years to come.

To find out more, watch the event video, or download the full or summary report visit kidney.org.au/deloittereport



Top left: Hon Pat Conroy MP. **Middle:** Hon David Littleproud MP. **Top right:** Mr Rob Mitchell MP with Xander Murko, Peter Murko and Lesley Tozer. **Bottom:** Panel Speakers - Prof. David Johnson, Prof. Alan Cass, Prof. Carol Pollock, Shailendra Tripathi, Alice George, Jodie Jeeves.

Ever wondered how you can make your voice heard to further kidney research?

Kidney Health Australia are verifying research studies and bringing them to you. Now you can see what research opportunities exist and how you can provide your opinion to change the future of kidney disease.

It's super easy:

1. Visit the research hub to see what verified research opportunities exist at kidney.org.au/research/consumer-research-hub
2. Apply directly to the researcher to participate.

RESEARCH NEWS

COLOUR ME IN

Here's a little drawing for you or a loved one to colour in while you're bored on dialysis or waiting around. Colouring in is very relaxing and gets your mind focused on a creative outlet.



BOOKS FOR KIDS

Did you know?

Last year we trained **4,325** health professionals! Find out more about what's available for GPs, nurses and doctors by visiting kidney.org.au/health-professionals

MOE'S SICK KIDNEYS

How do you explain to a child they have kidney disease? *Moe's Sick Kidneys* is an informative, illustrated book for children four to eight years old that could help navigate this difficult conversation. Moe has sick kidneys and takes his friend Milko on an adventure to tell him what it's like. Milko thinks Moe is very brave living with sick kidneys, having his blood cleaned and taking care of himself.



Cost: \$13 per book (incl GST and postage). Scan to buy online.

KIDNEY KIDNECTIONS: Stories of Families affected by Kidney Disease

The *Kidney Kidnections* book is written by the parent of a child with kidney disease. This uplifting book tells real stories of Australian families struggling to come to terms with a child diagnosed with kidney disease. It's an inspirational insight into their experiences, with beautiful photos and simple facts about kidney disease, how kidneys work, and more.



Cost: \$18 per book (incl GST and postage). Scan to buy online.

For organisation bulk orders email resources@kidney.org.au

Join the Kidney Kids and Youth Program

Join a community of kids and youth who understand what it's like to live with kidney disease. Whether you're a young person aged 0-24 years or a parent or guardian, there's support for you every step of the way. We're here to help build meaningful connections for life, understand your kidney condition and transition confidently from children's hospital to adult health care.

Scan the QR code below to join the Kidney Kids and Youth Program and receive a welcome pack with helpful information and some fun free goodies.



**“You are not alone.
Be brave. Be tough.
Have fun.”**

ES-CAPERS EVENTS

Enjoy a free day of fun at our Es-Capers Events. Es-Capers Events are a great way to connect with other local kidney kids, youth and families who are also impacted by kidney disease and build valuable peer support networks.

Join us for a fun day in your state.

REGISTER NOW DON'T MISS OUT!

WA: Saturday 1st April 2023, Adventure World – Bibra Lake (Registrations Closed)

NSW: Sunday 23rd April, YMCA Sydney Olympic Park Lodge

SA: Sunday 21st May 2023, Kingpin – Norwood

Scan QR code for more information and to register.



“It’s really good to see my sister making friends with other people who have been through the same thing.”
Kidney Sibling

KIDS CAMP

Kids and youth living with kidney disease can now enjoy exciting activities such as arts and crafts, visits to local tourist attractions, movie nights and more. During the four-night camp, our Kidney Youth Champions offer peer support and role modeling, showing kids and youth how to live well with kidney disease.

We understand that caring for someone with kidney disease can be challenging, that’s why Kidney Kids Camp also provides much-needed respite for caregivers. Trained doctors and nurses are in attendance to ensure your child is in safe hands whilst you take a well-deserved break.

Want an insight into our Kidney Kids Camp? Scan QR code to watch this video.



KIDNEY YOUTH CHAMPIONS

Our Kidney Youth Champions are passionate about improving the lives of kids living with kidney disease so you might see them visiting your paediatric unit, speaking at Kidney Health Australia events, or chatting on our closed Facebook group.

Register for monthly meetings by emailing kids@kidney.org.au or join our Kidney Youth Champions private Facebook group by visiting facebook.com/groups/KidneyYouthAustralia

Moderated by Kidney Health Australia staff and the Youth Champions, it is a safe place to connect and socialise (over 18s only).





MY precious GIFT

In his 70's, Des was diagnosed with high blood pressure. At first, it didn't stop him living the life he loved. He was an avid table tennis player, having won several Australian Championships.

As a nurse, Andrea understood the impacts of her father's diagnosis. With time, Des' kidney function declined until he went into kidney failure. He then began a journey that lasted 20 years with his family and nephrologist by his side. After 6 months of dialysis, Des went into palliative care.

Andrea plans to leave a gift in her Will to Kidney Health Australia to honour her father's legacy. *"My father was so precious to me. He was so extraordinary for his age, coaching table tennis into his 90's. We were so grateful for the care and guidance received from his health team, and the resources and support from Kidney Health Australia."*

Gifts in Wills are so gratefully received and are such a special commitment to future generations. Legacy gifts, no matter the size, have a lasting impact on the kidney community.

To find out more about how you can take this next step, please contact Roberta Armitage, Bequest Manager on Roberta.armitage@kidney.org.au or **03 9874 4383** or scan below to visit our website.



Did you know?

You can lose **90%** of kidney function with no symptoms. No wonder **1.8 million** of the 2 million Aussies who have markers of kidney disease don't know about it. Take the free risk test today by heading to [kidney.org.au/kidneyrisktest](https://www.kidney.org.au/kidneyrisktest)

Betsy's vision for a BRIGHTER FUTURE

At 85, Betsy's husband, Ollie was suspected of having kidney cancer. Whilst fortunately, no cancer was discovered after further testing, it was discovered that his kidney had significantly deteriorated. As a long-time supporter of Kidney Health Australia, Betsy has generously decided to leave a gift in her Will.

Through the Betsy and Ollie Polasek Foundation, Betsy has supported the programs and services of Kidney Health Australia, with a particular interest in research. Kidney Health Australia has recently launched the Kidney Research Alliance, aimed at increasing investment in kidney health research. The focus of the Alliance is on patient-focused outcomes and aligning research priorities that have the greatest impact on kidney health.

Betsy believes that giving back to organisations like Kidney Health Australia is crucial, especially in supporting research to improve people's lives. Kidney Health Australia has proudly invested more than \$30 million in research, thanks to the generosity of people who have left gifts in their Wills.

You too can leave a lasting legacy for future generations by considering leaving a gift in your Will to Kidney Health Australia
kidney.org.au/bequests



“ If you are in a position to do so, it's important to give back to organisations like Kidney Health Australia. I am a great believer in research, which in turn will help improve people's lives. ”

A SIMPLE WAY TO LEAVE A LEGACY

When it comes to thinking about our future, few of us have taken the steps to safeguard the people we love. Only 50% of Australians have a Will. Without a Will in place, the state decides how your estate will be distributed, and your final wishes may not be carried out.

Kidney Health Australia understands the importance of having an up-to-date Will, and have partnered with Safewill, a leading online Will writing service. Safewill allows Australians to complete their bespoke, legally binding Will in less than 20 minutes. Our supporters will receive a discount of 50% to help protect their loved ones, meaning you can prepare your Will today for just \$80.

After you've taken care of your loved ones, you may also wish to leave a gift to Kidney Health Australia. Leaving only a small percentage of your estate can have a lasting impact on people affected by kidney disease. A gift in your Will to Kidney Health Australia will advance research into kidney disease and improve treatments that will help save the lives of generations to come.



Find out more at
safewill.com/kidneyhealth

You deserve a holiday in 2023!

Book the Big Red Kidney Bus at one of these destinations ...



Ballina, NSW
Mon 30 Jan - Sat 25 Feb



Coffs Harbour, NSW
Mon 1 May - Sat 3 June



Port Macquarie, NSW
Mon 6 Mar - Sat 15 Apr



Nelson Bay, NSW
Mon 19 Jun - Sat 22 July



Orange, NSW
Mon 11 Sep - Sat 21 Oct



Blue Mountains, NSW
Mon 31 Jul - Sat 2 Sep



Mildura, VIC
Mon 29 May - Sat 8 Jul

Halls Gap, VIC
Mon 24 April - Sat 20 May



Batemans Bay, NSW
Mon 30 Oct - Sat 9 Dec

Daylesford, VIC
Mon 21 Aug - Sat 16 Sep



Lakes Entrance, VIC
Mon 2 Oct - Sat 4 Nov



Torquay, VIC
Mon 17 Jul - Sat 12 Aug



Philip Island, VIC
Mon 13 Nov - Sat 9 Dec

Wonthaggi, VIC
Mon 6 Mar - 15 Apr

free

Book your spot on the Bus today!

Bookings require two weeks notice.
Get in touch with us to secure your spot.

1800 454 363
kidney.org.au/bus
bigredkidneybus@kidney.org.au

Enjoy a much-needed holiday with the *Big Red Kidney Bus*

The Big Red Kidney Bus, Kidney Health Australia's mobile dialysis unit, makes holidays possible for those living with life-saving dialysis treatment. We know you can't take a break from treatment, so we bring the holiday to you.

Take a break from your dialysis unit and come onboard the Big Red Kidney Bus, staffed by highly professional and friendly renal nurses from our hospital partners.

The Big Red Kidney Bus has a 98% recommendation rating from previous visitors, so we welcome you to come along and experience the freedom and relaxation for yourself (and your family and carers who deserve a holiday too!) The best part? The Bus service is completely free and visitors are encouraged to attend unlimited sessions.

We've listened to visitors' feedback and planned new and popular destinations in 2023 including Blue Mountains, NSW and Philip Island, VIC.

Here's what Bus visitors who used the service had to say:

As dialysis patients know, if it wasn't for this Bus, we are only doing weekend or overnight trips. If you haven't tried the Bus trips, please think about it, and experience a great holiday, lovely people and caring staff.

What a professional experience. The Bus itself and its operations just blew me away.

No matter where in Australia you come from, you can join the Big Red Kidney Bus across any of the NSW or VIC locations. The experienced and friendly dialysis nurses welcome visitors to keep their regular haemodialysis routine onboard the Bus by booking as many sessions as they want in one of three comfortable dialysis chairs.

Getting away with family to explore new places, visit friends or enjoy a family trip over the school holidays is all possible with the Big Red Kidney Bus.

We kindly remind our Bus users and their travel guests that you will need to book accommodation separately. Our Buses will be conveniently located at various local holiday and tourist parks in each location, so you can enjoy the picturesque surroundings.

For more information, head to kidney.org.au/bus

This was my first time away from my dialysis unit. We finally 'broke the ice' so I can't wait for the next Big Red Kidney Bus experience.

KIDNEY HEALTH WEEK is coming!

The much-awaited **Kidney Health Week** is nearly upon us! May 21-27 get ready to make your voices heard and make some noise to help bring awareness to kidney health.

Register your interest at kidney.org.au/kidney-health-week



If you'd like a 2023 Bus poster or brochures sent to your office or renal unit please contact bigredkidneybus@kidney.org.au

what's ON?

KIDNEY KAR RALLY

13 - 19 August

Join us in our 34th year!

Mudgee to Narrandera via
Batemans Bay.

To find out more or register
for this year's event head to
kidneykarrally.org.au



TAKE A HOLIDAY

2023

Book a spot on the Big Red Kidney Bus, the renal unit on wheels, at popular holiday destinations throughout the year.

Get in touch with us
to secure your spot.

1800 454 363

kidney.org.au/bus

bigredkidneybus@kidney.org.au

Bookings require
two weeks notice.

KIDNEY HEALTH WEEK

21 - 27 May

A chance for everyone to get
behind the kidney cause and make
your voices heard!

Register here [kidney.org.au/
kidney-health-week](http://kidney.org.au/kidney-health-week)

BIG RED BBQ

Anytime!

By hosting a Big Red BBQ you can
raise awareness of the importance of
good kidney health and support the
treatments and research that can give
Australians living with kidney disease
the chance to live their best lives.

Sign up today by visiting
kidney.org.au/bigredbbq

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in this magazine?

Then you'll love the content of our monthly e-news.

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kidney.org.au/newsletter
or scanning below



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