

2019 CALENDAR OF EVENTS

14 March

World Kidney Day

8 - 14 April

Kidney Health Week

12 - 15 April

**World Congress
of Nephrology**

Melbourne

29 May - 2 June

Kidney Kids Camp

Lord Somers Camp,
Mornington Peninsula

9 - 17 August

Kidney Kar Rally

Port Macquarie to Armidale
via Capricorn Coast

YOUR KIDNEY

Connection

Summer 2019

WELCOME

As the new CEO of Kidney Health Australia, I'm delighted to introduce our first newsletter of 2019. If January is anything to go by, I can already tell this year is going to be busy and exciting, with several projects already well underway.



Work has commenced on our National Strategic Action Plan which will help shape the future of kidney care for Australians. The kidney community's response to the survey has been overwhelming and has proven how engaged and supportive our community is.

To improve support for our Indigenous communities, we are engaging in grassroots consultations across Australia to develop new renal guidelines. The statistic of 1 in 5 over the age of 18 having indicators of chronic kidney disease is alarming and highlights how critical this work truly is.

For our youth, we are running focus groups which will inform our Kidney Youth Program – designed to empower young people to maintain independence and – most importantly – to increase success rates in kidney transplantation, as currently approximately a third fail within five years.

In January, Professor Melissa Little, from the Murdoch Children's Research Institute, was awarded \$1 million in funding from the Government to further her groundbreaking research into developing kidneys from stem cells. Although it's long-lead research, a successful outcome will revolutionise the future of treatment.

Looking further ahead, Kidney Health Week will run from 8 – 14 April to coincide with the World Congress of Nephrology in Melbourne. Our objectives this year will be to amplify our messages around early detection and stress the importance of regular kidney health checks.

Making a difference for the many Australians affected by kidney disease wouldn't be possible without our partners and alliances and the generous support of our community, and I look forward to working with you this year as we continue to help save and improve the lives of people living with kidney disease.

Chris Forbes
Kidney Health Australia CEO

To see what's on, visit:
kidney.org.au/connect/whats-on



BIG RED KIDNEY BUS

VIC

25 February - 6 April 2019

**BIG4 Whalers Holiday Village,
Lakes Entrance**

29 April - 1 June 2019

**Torquay Foreshore Caravan Park,
Torquay**

11 June - 20 July 2019

BIG4 Swan Hill, Swan Hill

NSW

4 February - 16 March 2019

**BIG4 Batemans Bay Beach Resort,
Batemans Bay**

1 April - 4 May 2019

Discovery Parks, Dubbo

16 May - 29 June 2019

Discovery Parks, Ballina

The Big Red Kidney Bus is a free mobile dialysis service. To book or find out more visit: kidney.org.au/bus



MAKING PROGRESS

OUR NATIONAL STRATEGIC ACTION PLAN

Australia is one step closer to a national, coordinated action plan for kidney disease.

Kidney Health Australia is leading the development of the National Strategic Action Plan for Kidney Disease on behalf of the Commonwealth Government and is on track to deliver a plan which will have an enormous impact on the future of kidney care in Australia.

Over the past six months, Kidney Health Australia has been busy consulting with the kidney community including patients, carers, health professionals, state and territory organisations and government representatives.

In November 2018, there was a successful roundtable session in Melbourne involving government, nephrologists, renal nurses, National Consumer Council members, GPs, health economists, public health experts and other chronic disease charities.

The ideas generated during the lively discussions were used to develop a national kidney care survey. Distributed over December and January, the survey provided a valuable opportunity for the kidney community to share their voice and shape the outcomes of the action plan.

An overwhelming response was received with over 2,000 participating in the survey, including kidney patients, carers, clinicians, policy makers and researchers.



(L-R) Dr Lisa Murphy, Health Minister, The Hon Greg Hunt MP and Kidney Health Australia CEO, Chris Forbes

We are grateful to all of the community members who shared their experiences and expertise in the survey during the busy holiday period.

The next stages are to build on the results of the consultation and draft an action plan, which will be made available for public comment, before being finalised in June. Kidney Health Australia is proud to lead this vital piece of work on behalf of the kidney community.

Visit Kidney Health Australia at: kidney.org.au for regular updates on the National Strategic Action Plan

WORLD CONGRESS COMES TO MELBOURNE

More than 4,000 international delegates will descend on Melbourne from 12 - 15 April for the biennial World Congress of Nephrology.



The congress enables professionals from all parts of the world to exchange views, and supports the International Society of Nephrology's mission to advance sustainable kidney health on a global scale through education and training.

This year's focus is on glomerulonephritis and integrated end-stage kidney disease, and will cover topics relevant to global and Asia Pacific nephrology.

Watch Professor Stephen McDonald and Amber Williamson introduce the 2018 ANZSN Annual Scientific Meeting at: kidney.org.au/connect/whats-on

EMPOWERING YOUNG ADULTS WITH **KIDNEY DISEASE**

Focus groups around the country are canvassing the wants and needs of young adults living with advanced kidney disease as part of a new program to empower and support young people as they transition to adult healthcare.

Moving from paediatric to adult healthcare can be a difficult transition for young people, their families and healthcare workers.

To fully understand the challenges these patients face, we are holding focus group sessions with young people and their carers around Australia and invite the kidney community to get involved.

The Kidney Health Australia Youth Program was established in 2018 with the support of the Commonwealth Government to provide peer support networks, services and resources outside typical clinical settings for the estimated 700 young adults aged 15 - 24 years living with kidney disease.

Stephen Cornish, Kidney Health Australia's newly appointed Youth Program Manager, said the program was progressing well, with many insights gained to date.

"We've consulted with major clinical services and research groups to identify the needs and gaps in care, and we've held meetings with major paediatric and adult hospitals in all states.



"We've also collected information relating to youth services via a national survey of almost 100 renal units.

"It's been really valuable to meet with clinical staff and, along with the data and research, we have a better understanding of the issues facing young people as they transition from paediatric to adult care."

**Interested in joining the
Kidney Youth Program?
Email: info@kidney.org.au
or call 1800 454 363**

D NEWS

MASSIVE FUNDING FOR **MINIATURE KIDNEYS**

Congratulations to Kidney Health Week Ambassador, Professor Melissa Little from the Murdoch Children's Research Institute who has been given a massive funding boost for her ground breaking work which will turn human stem cells into mini kidneys.

Receiving almost \$1 million in funding from the Federal Government, the research project will use stem cells to develop kidneys with functioning tissue that are able to expand and function after being transplanted into the human body.

Although researchers have previously been able to implant stem cells to help regenerate damaged kidneys,

this would be the first time they are used to create new kidneys inside the body.

The work will take many years, but Professor Little hopes it will change the lives of those living with chronic kidney disease. If successful it will provide a lifesaving alternative to kidney transplants and dialysis.

We are proud to have supported her work.



Professor Melissa Little

Learn more about kidney health research by visiting: kidney.org.au/health-professionals



ASK US

Anything

Dr Shilpa

Dr Shilpa Jesudason MBBS, FRACP, PhD is a clinical and academic nephrologist specialising in obstetric nephrology, general nephrology and transplantation.

Question of the month "I don't have any back pain - does that mean I don't have kidney disease?"

This is a common question, and a good one. For many of my patients, learning that they have chronic kidney disease (CKD) comes as a surprise, because they haven't experienced any symptoms.

Despite what many people think, it is actually quite uncommon for people with kidney disease to have back pain, unless they have a kidney stone or kidney infection.

The kidneys sit quite high in your back, underneath the lower part of the rib cage, so lower back pain is rarely due to kidney disease.

Kidney stones may cause back pain when you pass urine, and blood may appear in the urine. A kidney or urine infection may give you back pain, as well as burning and stinging when you pass urine. If you do experience these problems, you should see your doctor straight away.

Unfortunately, most types of CKD are sneaky and silent. You can lose up to 90% of your kidney function without having any symptoms.

Symptoms of advanced kidney failure - such as fatigue, nausea, swelling and shortness of breath - present very late, and well after a substantial loss of kidney function. This is why awareness of risk factors and early kidney tests are so crucial as early detection can significantly slow the progression of kidney disease.

A simple blood test, urine test and blood pressure check may identify features of early CKD. If you show signs, your doctor or health professional will investigate further and put an appropriate treatment in place. This is often a simple process that makes a huge difference to your future kidney health. Prevention and early action are much better than dealing with advanced kidney failure.



Got a Question?

Contact our Kidney Helpline via email:

kidneyhelpline@kidney.org.au or call 1800 454 363

Learn more about the signs of reduced kidney function here: kidney.org.au/your-kidneys/detect

Get involved!

World Kidney Day is on 14 March 2019. Visit: worldkidneyday.org to join the call for 'Kidney Health for Everyone Everywhere'

WORLD KIDNEY DAY CALLS FOR UNIVERSAL HEALTH COVERAGE

With the increasing burden of kidney disease and the need for prevention and management strategies worldwide, it's fitting that this year's theme is 'Kidney Health for Everyone Everywhere'.



TREATMENT OPTIONS FOR **KIDNEY DISEASE**

If you have end stage kidney disease (that is, when your kidneys permanently stop working) your body cannot rid itself of extra water and waste products.

If this becomes dangerous to your health, you'll need to make some decisions about the kind of treatment you want. There are three treatment options for people with end-stage kidney disease: dialysis, a transplant or supportive care.

All three options are important pathways patients may decide to take in consultation with their kidney care team and family.



(L-R) David and Joy

Download your free copy of
**'An Introduction to Kidney
Disease Treatment Options'** at:
**[kidney.org.au/about-us/
resources-library](https://www.kidney.org.au/about-us/resources-library)**

This is Joy's story.

"My kidney function declined gradually. I was very particular in following the kidney diet and the advice of my specialist, but in hindsight I realise I really delayed the start of my haemodialysis for too long.

"I was very tired and generally lethargic and irritable, and my GFR (glomerular filtration rate) was six when I finally began dialysis."

Joy said that despite visiting her local centre, meeting the caring nurses and hearing from the specialist how much better she'd feel, she had still been hesitant. But after making the decision, she hasn't looked back.

"To my surprise, the treatment was painless apart from the quick needling process. The nurses were considerate and reassuring and made helpful suggestions like buying a heated blanket and Ugg boots because I felt the cold. Other patients were friendly and welcoming.

"Best of all was how much better I felt in so many ways. The fatigue was gone, and I felt alive again."

Unexpectedly, Joy also found that many of the toxins she'd been harbouring as a result of kidney disease, for example, the build up of hard plaque around her teeth, disappeared after commencing dialysis.

"The dentist couldn't believe the change!" she said. "Even though the routine of dialysis can be difficult, you can organise your life around it, and I found it definitely worth the effort.

"Now, thankfully, I have been blessed with a kidney transplant and am enjoying and participating in life to the full - but that is another amazing story!"

A big thanks to Joy for sharing her story with us. It's important to remember that every kidney treatment journey is different, and many people find themselves starting on one treatment type, then transferring to another.

CONNECT WITH
YOUR LOCAL
KIDNEY CLUB

Visit:
[kidney.org.au/connect](https://www.kidney.org.au/connect)
to find a club near you

Want to start your own club?
Call **1800 454 363**
to learn how

A COORDINATED APPROACH TO **REDUCING THE BURDEN OF DIALYSIS**

A landmark study on catheter use in dialysis patients has the potential to reduce thousands of cases of infections among people with kidney disease.

The George Institute's REDUCCTION study has collected data from over 4,100 people and 6,100 catheters from 42 Australian and New Zealand hospitals to date, in a bid to find out more about their use and infections they may cause.

Dialysis catheter-associated infections are a serious and costly burden on patients and the healthcare system. Though widely used and essential to the delivery of life-sustaining dialysis treatment, catheter

management practices vary, and little information is available about the infections they cause.

The REDUCCTION study marks the first phase of a coordinated national approach to reduce dialysis catheter bacteraemia, a common blood infection that can cause life-threatening infections such as sepsis or septic shock.

In an average Australian dialysis unit, catheters result in between 15 and 33 episodes of bacteraemia and two and four deaths per year, at a cost of \$330,000 - \$770,000 annually.

Dialysis patients are especially susceptible to infections, including those with end

Learn more about the
REDUCCTION study at:
georgeinstitute.org.au

stage kidney disease, who receive dialysis treatment through central venous catheters - narrow tubes inserted through the chest into a large vein near the heart.

Renal units participating in the REDUCCTION study will follow a care plan based on the latest research, and the findings of this study will be released in 2020.

BRKKB

IAN'S JOURNEY TO THE **BIG RED KIDNEY BUS**

This January we welcomed 65 year-old Ian as a first time patient on the Big Red Kidney Bus.

Ian was born with only one kidney, on his left side, but wasn't aware of any issues until his early forties. Despite life-long symptoms of frequent urination, Ian thought that was simply the way life was, because he presented no other symptoms.

After his application for income protection insurance was declined based on positive tests for blood and protein in his urine, Ian was tested and a biopsy confirmed he had issues with his left kidney. Ian has since been on home haemodialysis with the help of his wife, Georgina.

This year, after 44 years in education, Ian made the difficult decision to retire due to the challenge of working full time while undergoing dialysis four times a week.

"Even though my dialysis is generally undertaken after work hours, at home, there are some days when I struggle to fulfil my duties at full capacity - so I needed to focus on my health as opposed to my occupation," explained Ian.



Ian dialysing in the Big Red Kidney Bus, Royal Botanical Gardens, Melbourne, Victoria

As a first time user of the Bus, Ian enjoyed a break from the monotonous routine of four-hourly dialysis, four times a week, at the same place. He also appreciated the opportunity to travel and catch up with friends without the constraints of returning home for treatment every second day.

View VIC and NSW locations of the Big Red Kidney Bus at: kidney.org.au/bus

A new national research and consultation project will improve Indigenous kidney healthcare and create a healthier future for Aboriginal and Torres Strait Islander Peoples.

Kidney Health Australia has received support from the Commonwealth Government to consult with 16 communities in metropolitan, regional and remote areas across Australia, to gain insight into culturally-appropriate ways to support chronic kidney disease and develop specific clinical guidelines.



Nari dialysing at Hampstead Dialysis Centre, Northfield, South Australia

The first of these consultations were held in Adelaide and in partnership with the Improving Aboriginal Kidney Care Together project, led by Dr Janet Kelly from the University of Adelaide and the South Australian Health and Medical Research Institute.

The group of kidney and diabetes patients, their families and carers discussed all stages of kidney disease, with a focus on how to improve education and care.

Nari, a Ngarrindjeri and Yorta Yorta woman who attended the Adelaide session with her dad and aunt, said she found the consultations useful because she and her family could hear about the different ways people get started on dialysis, and how they are treated by nurses and doctors.

Nari is on dialysis three times a week and her family has lost their mother, brother and sister to kidney disease.

"When I started my kidney journey, I had the support of my mother, brother and sister, who were on dialysis."

"As a member of the reference group, I can help my people who have kidney problems or are starting dialysis."

When asked what she would say to others about the consultations, Nari said: "I would invite them to come to the next one, especially families of people who don't know what dialysis patients go through."

Grassroots consultations of this nature will help Kidney Health Australia ensure that clinical guidelines are relevant and reflect what communities want and need.

Each stage of the process - from organising gatherings through to communicating outcomes - will be guided by the Indigenous communities. The remaining meetings will gather further insights and should be complete by late 2020.

Aboriginal and Torres Strait Island Peoples are almost four times more likely to die from kidney disease than non-Indigenous Australians, and recent research shows almost 1 in 5 over the age of 18 have indicators of chronic kidney disease.

This project will have a significant impact on the future health and wellbeing of Aboriginal and Torres Strait Island Peoples.



SUPPORT AND RECOGNITION FOR **HEALTH PROFESSIONALS**

An innovative new program is supporting GPs, practice nurses, aboriginal health workers and other primary care health professionals to drive best practice detection and management of chronic kidney disease (CKD) throughout Australia.

The CKD Ambassador Program provides health professionals with practical tools and resources, dedicated support and recognition for their important work to improve the lives of people living with kidney disease.

Why become an ambassador?

Participating in the program has a range of benefits, including:

- Improved quality of patient care
- Increased efficiency and income
- Increased confidence in detecting managing and referring CKD patients
- Contributing to the development of educational resources
- Networking opportunities
- Media, event and promotional exposure for your practice
- Access to Kidney Health Australia resources, services and support

The program is an accredited as a category 1 quality improvement activity.

What's involved?

Participants will assess people for CKD risk factors and implement a framework to effectively detect and manage kidney disease in their practice.

The program takes around three to six months to complete, at which time participants will be endorsed as a Kidney Health Australia CKD Ambassador and awarded continuing professional development (CPD) points.

Expressions of interest are now open! Apply at: kidney.org.au/ckd-ambassador



RESOURCES

IMPROVING KIDNEY HEALTH **WITH EDUCATION**

Primary care professionals have the power to significantly improve health outcomes for people living with chronic kidney disease (CKD), and reduce the burden of the disease on the community.

Kidney Health Australia's Primary Care Education Program provides a suite of education and resources for health professionals to increase awareness and implementation of best practice detection and management of CKD.

The world-class program is offered in a range of formats and includes readymade education (such as PowerPoint presentations), sourcing a local presenter, providing accreditation on request and supplying supporting and

complementary resources. Workshops and learning modules are flexible and can be run face-to-face, for groups as small as 10 and as large as 100, ranging from intimate practice meetings to large conferences. Primary care professionals can decide which package suits them best.

To access free CKD online education modules, visit: thinkgp.com.au/kha

Modules are accredited for Continuing Professional Development with The Royal Australian College of General Practitioners (RACGP), The Australian College of Rural and Remote Medicine (ACRRM) and Australian Primary Health Care Nurses Association (APNA).



Book a Primary Education Workshop at: kidney.org.au/health-professionals



By Kidney Health Australia



(L-R) Patricia and Keith pictured with their new Subaru Forrester

Are you feeling lucky?
Support people living with kidney disease and play the K Lottery at: kidney.org.au/lottery

"Congratulations YOU'VE WON THE LOTTERY!"

Patricia couldn't believe her ears when she heard these words over the phone in December.

Patricia, our latest National Kidney Health Australia K Lottery winner, never dreamed she'd win. In fact, she assumed our phone call to tell her the good news was a prank.

"I didn't believe it," she said. "I thought it was a hoax phone call but she kept assuring me it wasn't. I couldn't stop smiling all day."

Patricia told us she had kidney issues at a young age and to say thanks for the support she received, she and her husband Keith had been entering

the K Lottery for many years. Their fabulous prizes include a new 2019 Subaru Forrester plus \$10,000 in gold. "Our second car is 15 years old and needs some work, so it's great timing," Patricia said.

As a first-time winner but long-time supporter, Patricia recommends everyone play K Lottery - if not for the cause, then definitely for the prizes. "Go for it! Your chances are much higher than some other lotteries. I mean, I won, so anyone can win!"

Your support makes a difference! Each lottery entry supports Kidney Health Australia's education, advocacy, research and support programs.



(L-R) Dr Marie Ludlow, General Manager of Community Programs, thanking Bronte for his contribution

BRONTE'S KIDNEY JAM RAISES OVER \$1,000!

Bronte was diagnosed with kidney disease a few years ago, and soon after learned he would need to commence dialysis. Terrified of needles, he spent the next 12 months learning about the importance of the lifesaving treatment with the support of his family.

On his first day of dialysis, Bronte arrived scared and in tears. Luckily, he had the support of a close family member who promised him a concert in his honour to help distract him from the needles.

Bronte bravely commenced dialysis and last November he was rewarded with his big concert, raising over \$1,000! Bronte hopes the concert raised awareness of kidney disease and inspired other people to overcome their fear of dialysis.

To host your own fundraising activity for Kidney Health Australia, email: info@kidney.org.au or call 1800 454 363

ZINGY SUMMER SPRING ROLLS

Too much salt (sodium) in our diet can increase blood pressure, which is bad for our hearts and our kidneys!

Most of us eat more salt than we should, and our taste buds have become used to salty foods. One simple way to reduce our intake is to use herbs and spices instead of salt to flavour food.

Try creating different versions of this delicious, zesty, kidney-friendly recipe using coriander, chilli, ginger, garlic, Thai basil, or Vietnamese mint.

INGREDIENTS

- ½ cup cabbage, finely shredded
- ½ cup carrot, grated
- ½ cup cooked chicken mince (or shredded BBQ chicken breast)
- ¼ cup fresh mint (Vietnamese if you have it)
- 2 tbsp spring onion, finely chopped
- 1 tbsp olive oil
- ¼ tsp pepper
- 1 cup vermicelli or clear Asian rice noodles
- 8 sheets of dried rice paper
- Sweet chilli sauce

Makes: 8 rolls. Serving size: 2 rolls



Salt Reduced Zingy Summer Spring Rolls

METHOD

- Soak noodles in hot water until tender, then drain.
- Heat olive oil in a pan, add chicken and pepper and stir until cooked. Drain off juices.
- Gently mix noodles, vegetables and chicken mince. Divide into eight portions.
- Individually dip rice paper sheets into a bowl of warm water to soften.
- Place one sheet on a chopping board and place a portion of the filling in the middle of the sheet.
- Add some of your fresh herbs and any other flavourings.
- Fold the end of the sheet closest to you over filling.
- Fold in both sides, then roll away from you until a roll is formed.
- Serve rolls with 1 tbsp of sweet chilli sauce per serve.

Nutritional analysis per serve:

- Energy 821kJ
- Protein 9g
- Fat 7g
- Carbohydrates 23g
- Sodium 98mg
- Potassium 160mg
- Phosphate 88mg

For more salt reducing tips, download 'Salt and your Kidney' factsheet from: kidney.org.au/about-us

WORLD SALT AWARENESS WEEK 4 - 10 MARCH

It's time for ACTION on salt.

Take part in this important week and visit: worldactiononsalt.com/awarenessweek



HONORARY LIFETIME MEMBER **PETER LANYON**

Kidney Health Australia recognises
30 years of support

Kidney Health Australia is delighted to award Peter Lanyon the first ever Honorary Lifetime Membership for his significant contribution to raising awareness and financial support for kidney health. We asked him to share a few of his favourite memories with us.



How did you first hear of the Kidney Kar Rally?

I first heard of the "Unique Cars Kidney Kaper" in early 1989, via an article in the Sydney Daily Telegraph newspaper. There was a picture of an outback dunny being blown up in the middle of Rosehill Racecourse, in the tradition of Galignite Jack Murray.

Why did you join?

My daughter, Jodie, was a Kidney Kid and at the time, I was a bit of a rev head with dreams of one day becoming a race-car driver. A lack of money, connections and more importantly, not much talent, put a bit of a dampener on that dream - until the Kidney Kar Rally came along. I saw an opportunity to combine my love of family, and my desire to - through supporting research - find a cure or better courses of treatment of kidney disease, to ease the regime that kidney disease can put on a family unit, and to get involved with motorsport.

Do you have a favourite course from over the years?

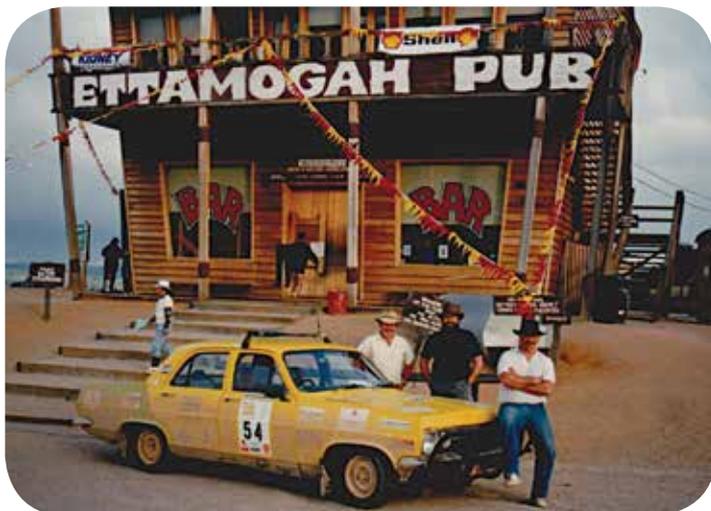
Each year offers something different. From the diverse terrains of corrugations, creeks, narrow forest tracks, and red dirt tracks to the locations including the Nullarbor, Uluru, Tasmania, the Victorian high country, and the outbacks of New South Wales and Queensland - it's impossible to pick a favourite.

It's hard to imagine anywhere else in the world that has more friendly and hospitable people than the people of the outback.

What does becoming an honorary lifetime member mean to you?

How do you honour one tree in a forest of trees? I have never been one to seek reward or favour, so to be recognised as an Honorary Lifetime Member is a very humbling experience for me. To be honoured for doing something that I enjoy is a wonderful feeling.

This year's rally route is from Port Macquarie to Armidale via the Capricorn Coast, from 9 - 17 August. Register now at: kidneykarrally.org.au



Peter Lanyon with his 1989 team



(L-R) Kidney Kar Rally veteran, Peter Lanyon and daughter Deb, registering in Goulburn for the 30th annual Kidney Kar Rally in 2018

Sign up to receive this newsletter. Visit: kidney.org.au/subscribe



Save the date

**Kidney Health Week
8–14 April, 2019**



**To get involved contact:
info@kidney.org.au**