

Newsletter # 3 April 2023

Welcome to our second newsletter for 2023!

In this edition, you will find:

- Kidney Bites has launched!
- SONG-Tx: Transplant cancer outcomes survey now open
- Australasian Kidney Trials Network Consumer Advisory Board: Expressions of interest invited from ATSI or Maori descent.
- Research Seminar – Decision-making at the time of kidney transplant offer
- New resources added to the BEAT-CKD patient's resources page
- Tree of Hope- honouring kidney donors
- Meet Jasmin Mazis, one of our CRE-PACT team!
- Spotlight on our Network – ANZDATA
- Upcoming news and events

Kidney Bites has launched!



A big thank you to everyone who came along to the first Kidney Bites meeting! It was a warm and friendly event joined by people from metropolitan, regional, and rural areas in Queensland, Victoria, New South Wales, and South Australia. People shared some of their stories and expressed what they hoped to gain by participating. The discussion covered a range of topics such as education, access to information, and the need to ensure that research meets patients' needs. We also collectively agreed that the Kidney Bites theme song should be "We are the Champions" (who doesn't love Queen?). We can't wait to see everyone again at our next meeting, details are below.

Our next Kidney Bites meeting
Date: 26th April 2023
Time: 4 p.m. AEST
Location: Zoom <https://uni-sydney.zoom.us/j/86876780289>

Who should join? Anyone living with kidney disease and their family members, who are curious to learn more about research.

This month we are joined by a panel of researchers with lived experience of chronic kidney disease who will share their experience and answer your questions about consumer involvement in research. We welcome questions as they arise, but it would be great if you could send some of your questions to one of the PEOs listed below before the meeting.

Patient Engagement Officer contact details:

Anastasia Hughes: Anastasia.hughes@sydney.edu.au

Amanda Sluiter: amanda.sluiter@sydney.edu.au

Helen McLennan: helen.mclennan@sydney.edu.au



SONG Transplant - Cancer Outcomes Survey

Patients, caregivers, and health professionals with experience or interest in kidney transplantation are invited to complete this survey on which cancer outcomes you think should be measured and reported in research (clinical trials) in adults. If you are interested, please follow this link to read more information and complete the survey.

Survey to close by the 5th of May 2023.

To participate visit

https://sydneypublichealth.au1.qualtrics.com/jfe/form/SV_9ELb5ze3mk46Owe



Expression of interest to be a member of the Consumer Advisory Board for the Australasian Kidney Trials Network (AKTN).

Do you have lived experience of kidney disease, as a patient or caregiver? Would you like the chance to shape kidney disease research? Do you identify as Aboriginal and/or Torres Strait Islander or Maori?

AKTN wants to make sure that clinical trials are designed and run in a way that is meaningful to patients and caregivers and focuses on outcomes that are important to them.

The AKTN Consumer Advisory Board will help ensure that trial designs and documents provided to the kidney community are clear and useful, including when the trial results are shared with the kidney care community.

[Expression of Interest at https://aktn.org.au/eoi/](https://aktn.org.au/eoi/)

BEAT-CKD Research Seminar Series

We'd like to invite you to the next BEAT-CKD/CRE-PACT PG ECR presentation for 2023.

BEAT-CKD/CRE-PACT PG ECR presentation

Monday: 24th April at 2:30 pm – 3:30 pm (AEST)

Speaker: Dr Alison Weightman

Topic: Decision Making at the Time of Kidney Transplant Offer: A Bioethics Perspective



Deceased donor kidney transplant offers can require complex decision-making. These offers often occur at inopportune times (e.g. the middle of the night) and can involve weighing up a range of potential risks and benefits (e.g. immune matching, donor comorbidities, risks of infection or cancer transmission). Alison will be presenting the interim findings from an interview-based study involving transplant doctors, kidney doctors, and transplant patients about transplant offer experiences, together with a discussion about the ethical principles involved.

If you are interested in attending, please email research@beatckd.org

Consumer resources page

The CRE-PACT has updated its consumer and carers resources page. Grouped under easy-to-find headings, our team has done all the work for you and has hand selected some of the best resources available on consumer and community engagement. Compiling these documents in one place means that you don't have to spend time searching the internet to find reputable information.



Australasian Kidney Clinical Trial Network

What is a clinical trial?



Cochrane

What are systematic reviews?



Core Outcome Measures in Effectiveness Trials

What are core outcomes?

To see our full resources page go to <https://beatckd.org/>



Tree of Hope

To highlight the importance of World Kidney Day, the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) and the South Australian Health and Medical Research Institute (SAHMRI) hosted the Tree of Hope.



The Tree of Hope initiative is a long-term project. Each leaf on the branches represents a very special person. They gave the gift of life to people they would never meet through organ and tissue donation.

For more information, please visit <https://herdofhope.com.au/tree-of-hope-2/>

Meet members of our CRE



Meet our Patient Engagement Officer (PEO) Jasmin. Jasmin works for the Australia and New Zealand Dialysis and Transplant Registry based at the South Australian Health and Medical Research Institute (SAHMRI - above photo) and is one of the PEOs within the CRE-PACT.

Within the CRE-PACT Jasmin supports the partnership portfolio, communications, and policy. The role of the partnership portfolio is to support stakeholder engagement and knowledge exchange to communicate research findings and build national and international relationships that support the implementation of our project findings.







Jasmin is a qualified Registered Nurse with over 20 years of healthcare experience. Jasmin has furthered her studies in cancer nursing and has a Master's in Public Health. Having worked in both public and private hospitals as well as within the community, Jasmin enjoys patient engagement and aims to connect consumers and researchers together to improve the lives of people with kidney disease.

Spotlight on our Network: The Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)



Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collects clinical data from dialysis and transplant services all over Australia and New Zealand and uses it to answer a wide range of questions relating to outcomes for people with chronic kidney disease.

What is ANZDATA?

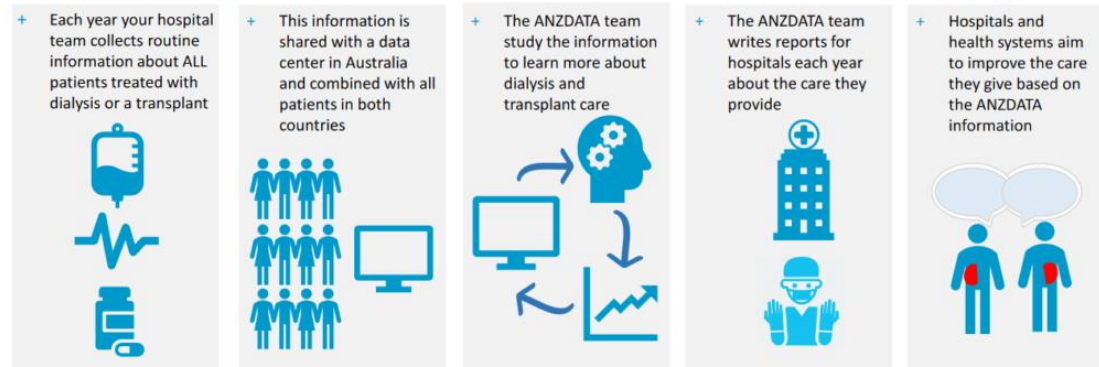
- + ANZDATA helps hospitals learn whether patients are getting good dialysis or kidney transplant care. 
- + ANZDATA is funded by the Australia and New Zealand governments and has been working since 1978. 
- + ANZDATA is a data store of clinical information about all the people who have received a kidney transplant or been treated with dialysis in Australia and New Zealand. 
- + The collection of treatment information involving thousands of people helps hospitals to learn about the health and wellbeing of those patients and ways to improve treatment. 

START

Months

Years

END



In New Zealand, the sharing of health information with ANZDATA is approved by the Office of the Privacy Commissioner as essential to measuring care quality while protecting the privacy of patients.

Routine patient information such as the type of kidney disease, treatment, test results, and medications is collected and analysed to find out things such as how many people have a particular type of kidney disease, how treatments change over time, or what services might be needed in the future. To find out more contact anzdata@anzdata.org.au



World Transplant Games - April 15th to 21st

Perth, Australia is home to the 2023 World Transplant Games. It promises to be a games like no other, bringing the transplant community back together. This will be the third time the Games have been staged in Australia; good luck to everyone involved!

Filter Fun Park™ The Musical

Filter Fun Park™ The Musical – Sunday, May 7th (Flemington, Victoria)

Filter Fun Park™ is an educational musical aimed at children aged 7 – 14, however, all audience members big and small will enjoy the catchy original tunes, important health messages, and delectably smooth food puns. Get your tickets at www.eventbrite.com.au/e/filter-fun-park-the-musical-tickets-556415061427

International Clinical Trials Day - May 20th

Clinical Trials Day is an opportunity to raise awareness about the importance and benefits of clinical trials and recognise all those hard-working professionals in the clinical trials sector that continue to improve the quality of life of many patients worldwide. On May 20th we recognise the people who conduct clinical trials and say “thanks” for what they do every day.

Kidney Health Week – May 21st-27th

The much-awaited Kidney Health Week is nearly upon us! Get ready to make your voices heard and make some noise to help bring awareness to kidney health. Sign up for Kidney Health Week 2023 before Monday, April 24th. Sign up at <https://kidney.org.au/get-involved/kidney-health-week>