

START



2018 ANNUAL REVIEW

EDUCATION
ADVOCACY
RESEARCH
SUPPORT

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ABOUT **KIDNEY HEALTH AUSTRALIA**

For 50 years, Kidney Health Australia has been dedicated to improving health outcomes and quality of life for people living with kidney disease, their families and carers.

We aim for a future where all Australians can have healthy, functioning kidneys for life. For this to happen, we educate the community on ways to manage their kidney health, and understand the risk factors of kidney disease. For general practitioners and other health professionals, we ensure our education programs better equip them to detect the signs of kidney disease at the earliest stage possible. We also fund critical research to champion breakthroughs in the management, treatment and eventual cure of kidney disease.

For those patients living with kidney disease, Kidney Health Australia's world class clinical guidelines (KHA-CARI) support clinicians in providing the appropriate care and management, while on the ground, our Kidney Health services give families affected by the disease support where they need it most in managing their daily lives. Our Big Red Kidney Bus service has enabled countless families to have a holiday together, knowing that remote dialysis is at hand. For children living with kidney disease, our Kidney Kids Camp provides a happy, secure place to have fun with peers. And our transplant houses have been a home away from home for families living in regional areas, who need to temporarily uproot their lives to undergo the kidney transplant process in major cities.

We continue to advocate for kidney health to be everyone's priority, and we will continue to work closely with the government, medical community and our kidney community to make this goal a reality.

OUR WORK

Our work includes:

- providing vital services to people living with kidney disease, their families and carers
- educating health professionals on prevention and detection of kidney disease
- funding important research
- advocating to government and industry to improve kidney disease awareness in Australia.

OUR COMMUNITY

People with kidney disease, families and carers

Advisory groups

Ambassadors

Health professionals

Community supporters and fundraisers

National Consumer Council

Staff

Volunteers



CHALLENGES

Silent killer: 90% of kidney function can be lost without experiencing any symptoms

1 in 3 people in Australia is at risk of kidney disease

Kidney disease currently affects an estimated **1.7 million** Australians

Every day **65** Australians die with kidney-related disease

Indigenous Australians are **4 times** more likely to die of kidney disease

KEY IMPACTS

Support

1000 patients able to enjoy family holidays with mobile dialysis service

40 families housed for **299** days in transplant houses

100 kids with kidney disease have fun at camp

Research

\$250K in grants to improve quality and duration of life for people with kidney disease



Education

45,000 health professionals reached through our Primary Care Program

500,000+ information resources distributed

Prevention and Detection

11,837 kidney risk tests completed to highlight to people their risk of kidney disease



“Kidney disease is a highly undiagnosed condition and most are tragically unaware they are affected until it’s too late. It’s a silent killer but it doesn’t have to be.”

A MESSAGE FROM **THE CHAIR**

At our 50th Anniversary celebrations at Admiralty House in September, our Patron and His Excellency the Governor General of Australia, Sir Peter Cosgrove eloquently reminded us of the difference Kidney Health Australia has made to many lives over the last half century, providing information and support to patients, education to clinicians and investment in research to prevent and improve the outcomes of those affected by kidney disease.

The 50 year celebration also marked the announcement of the inaugural Mark Colvin scholarship, a partnership between the Australian Broadcasting Corporation (ABC) and Kidney Health Australia. Mark was best known and much loved for his nightly delivery of PM in Sydney on the ABC. He had a personal journey with kidney disease, having been on dialysis and then having received a kidney from a colleague and friend. Unfortunately he passed away in 2017 but his passion to help those with kidney disease and his passion for organ transplantation lives on. Alex Tighe was awarded the inaugural Mark Colvin scholarship and we look forward to him raising the awareness of kidney disease.

Despite the continued best efforts of Kidney Health Australia and the broader community, kidney disease continues to be a silent killer with 65 Australians dying with kidney related diseases every day. Kidney disease accounts for more deaths in Australia than the aggregate of breast cancer, prostate cancer and road accidents each year and is overrepresented in our Aboriginal and Torres Strait Islander communities. Because 90% of kidney function can be lost without experiencing any symptoms, kidney disease is a highly undiagnosed condition and most are tragically unaware they are affected until it’s too late. It’s a silent killer but it doesn’t have to be.

Implementing strategies to limit the development and progression of kidney disease to save lives of Australians forms a key platform of the National Strategic Action Plan for Kidney Disease (NSAPKD), which has been commissioned by the Federal Government. Kidney Health Australia has coordinated this plan on behalf of stakeholders and we look forward to their support to achieve ambitious but necessary goals.

This year was a time of change for us. Dr Lisa Murphy provided excellent leadership as interim CEO until October 2018. The Board and staff are highly appreciative of her leadership in this role and continued commitment to Kidney Health Australia. Chris Forbes was appointed as CEO in October 2018. Given the inexorable rise in chronic kidney disease in our community, along with the parallel increase in obesity, cardiac disease and diabetes we have set Chris ambitious goals which he has wholly embraced.

I would like to thank my co-directors who are entirely and selflessly committed to the cause of eradicating kidney disease.

Finally, thanks to our staff and supporters for their ongoing commitment to improving the lives of people affected by kidney disease.

Our patients need Kidney Health Australia to remain a vibrant organisation, responsive to patient needs. We aim to deliver on the needs of people affected by kidney disease and look forward to doing so with your support into the future.

Professor Carol Pollock Chair
MB, BS, PhD, FRACP, FAAHMS



“The fight continues. More than ever, we need to boost awareness and funding to save lives.”

A MESSAGE FROM **THE CEO**

I felt privileged to join Kidney Health Australia in October as Chief Executive Officer and want to thank the Board for their support over the past months.

In our 50th year, we have taken greater steps in shaping our plans for the future and collaborating with the Australian community on those plans.

Firstly, we have taken on the role of preparing the National Strategic Action Plan for Kidney Disease, which recognises the growing impact of kidney disease on the community. We are collaborating widely across the kidney community and this experience has demonstrated how engaged the kidney community is and how driven they are to fight this insidious disease. This Action Plan will be presented to the Minister for Health in 2019 and we call upon the Government to fund key action items as demanded by those affected.

Thanks to the Hon Ken Wyatt, Minister for Indigenous Health, Kidney Health Australia was also commissioned to undertake Indigenous Community Consultations to help guide the Kidney Health Australia - Caring for Australasians with Renal Impairment (KHA-CARI) guidelines specifically related to Indigenous Health. The guidelines will provide culturally safe information and tools around the areas of kidney disease, dialysis and transplantation. We welcome this opportunity to support Aboriginals and Torres Strait Islanders living with kidney disease.

We continue to be a lifeline for people and families dealing with kidney disease in managing their condition. For people in remote areas having to uproot their lives temporarily while facing kidney transplants, our transplant houses have been a haven. And our Big Red Kidney Bus continues to make it possible for people on dialysis to spend precious holiday time with their families.

But these services only scratch the surface in terms of the level of care and medical access required for our kidney community, especially in regional areas. Which is why continued funding support is crucial to enable us to improve and extend our reach, and have a greater impact on the lives of people affected by kidney disease.

Chronic kidney disease is a silent killer and its prevalence is growing at an alarming rate, which is why more than ever we need everyone to join our fight in putting a stop to this disease.

Finally, I want to recognise and thank Dr Lisa Murphy for her leadership during her time as interim CEO. I am delighted that Lisa has taken on her new role involving Policy and Advocacy on behalf of Kidney Health Australia and those affected by kidney disease.

Chris Forbes Chief Executive Officer



“The patient, carer and community voice continues to underpin and inform all the work we do.”

CLINICAL DIRECTOR REPORT

2018 was a very productive and progressive year at Kidney Health Australia. Our Clinical and Community teams responsible for our national education services and patient resources, and service programs such as the Big Red Kidney Bus, transplant houses and kids camp, were admirably led by Dr Marie Ludlow. Under her guidance, our teams had a busy year working to serve and support thousands of patients, carers and health professionals across Australia.

Our national education team continued to deliver hundreds of hours of face-to-face and online education to primary care professionals across Australia. We continue to value the dedication and support of the Kidney Health Australia’s Primary Care Education Advisory Committee for Kidney Health Australia (PEAK) committee under the chairmanship of Professor David Johnson.

A key task for PEAK was the development of the fourth edition of the highly successful and widely utilised Chronic Kidney Disease Management in General Practice handbook, to be delivered in 2019. This committee provides endless volunteer hours to ensure our activities in the primary care education space, to enhance the early detection and management of kidney disease, are based on gold standard clinical practice principles.

In 2018, we also strengthened our collaborations with research partners by recommencing research funding and awarding five scholarships valued at \$50,000 each.

Consumer engagement for research is becoming a rapidly developing area in the kidney space. We recognise that consumers should be involved not just as subjects but also in the development and conduct of research to ensure it is relevant and meaningful.

A major research partnership for 2018 was with the Better Evidence and Translation in Chronic Kidney Disease (BEAT-CKD) research consortium. Our collaboration led to a very exciting new initiative of a dedicated session for consumers at the ANZSN Annual Scientific Meeting in Sydney in September 2018. Two sessions were live streamed. Hundreds of consumers were able to join in online from the comfort of their homes or view later via YouTube. This enabled us to share updates about kidney research in Australia to a broader audience.

The patient, carer and community voice continues to underpin and inform all of our activities and endeavours.

A/Prof. Shilpa Jesudason Clinical Director
MBBS, FRACP, PhD

BOARD MEMBERS



(L-R) Rhonda Renwick, PJ Hartshorne, Peter Haddad, Mono Ray, Prof. Carol Pollock, David Morgan, Sally Farrier. Absent: David Parker.

Prof. Carol Pollock Chair

MB, BS, PhD, FRACP, FAAHMS

Professor Carol Pollock was appointed to the Board in December 2014, and appointed Chair in December 2017.

An inaugural fellow of the Australian Academy of Health and Medical Sciences, Carol is recognised as a 'distinguished Professor' by the University of Sydney and was the 2014 recipient of the Ministerial Award for Excellence in Cardiovascular Research.

Carol was Scientific Chairman of the 2013 World Congress of Nephrology and is currently Chair of the NSW Bureau of Health Information, the NSW Cardiovascular Research Network, Deputy Chair of the Australian Organ Tissue and Transplantation Authority and Director of Certa Therapeutic Council of NHMRC.

Sally Farrier Deputy Chair

BE (Hons), MBA, GDipAppFin, MAICD

Sally was appointed Deputy Chair in December 2017.

She is a professional non-executive director, with extensive experience in the utility, infrastructure and consulting sectors and in working with governments and regulators. Sally has strong expertise in governance, strategy and risk management following a career in consulting and corporate advisory.

Peter Haddad

AO, MSc, BEc

Peter was appointed to the Board in June 2017.

Peter retired as a logistics officer in the Australian Army in 2005 at the rank of Major General and is now the principal of a consultancy company specialising in defence industry, logistics and supply chain management. Peter is currently the Strategic Advisor to the Victorian Defence Alliances - Victoria, and he is an Adjunct Professor and the Chair of the School Advisory Board for the School of Business, Information Technology and Logistics at the Royal Melbourne Institute of Technology University.

BOARD MEMBERS

David Parker

AM, BEc (Hons), LL.B (Hons)

David Parker was appointed to the Board in April 2010, having previously chaired Kidney Health Australia's National Consumer Council.

At present, David is Chairman and CEO of the Australian Clean Energy Regulator. Previously, he was a Deputy Secretary in the Commonwealth Government's Department of Agriculture and Water Resources and a Deputy Secretary in the Department of Environment and the Commonwealth Treasury.

Monojit (Mono) Ray

BSc, LL.B, LL.M, Grad Dip Legal Practice, GD Enterprise Management, Solicitor of the High Court of Australia and the NSW Supreme Court

Mono Ray was appointed to the Board and the Finance, Audit and Risk Committee in June 2017.

Mono has held numerous leadership and non-executive roles throughout his career and is currently the Managing Director and co-founder of ConnectAlex.

He was previously a senior partner at PwC and served on a number of industry bodies, and has also worked closely with State and Federal regulators to design policy and legislation. Mono brings organisational leadership, business innovation, strategic management and communication expertise to the Board, with experience working in professional and financial services, at Board, Senior Executive and Ministerial levels.

Rhonda Renwick

GradD BA, Bachelor of Science PSY, MAICD

Rhonda Renwick was appointed to the Board in June 2017.

Rhonda is the sole director of Latrobe Valley Bus Lines and the founder of Kindred Spirits Foundation, with extensive expertise in indigenous health and community-based enterprises. Kindred Spirits Foundation has been a driving factor in community projects such as the Big Red Kidney Bus initiative.

PJ Hartshorne

BSc Civ. Eng, MBA

PJ (Peter Jon) Hartshorne was appointed to the Board in April 2008.

PJ is Managing Director, partner and founder of The Infinity Group of companies, established in 1994 as a private professional services business in Australia, India and the United Kingdom. He is also Chairman of Scholaris International Ltd and Redgum Corporate Pty Ltd. PJ is also a member of Kidney Health Australia's Remuneration and Succession Planning Committee and was appointed Chair of the Finance Committee in March 2016.

David Morgan

BA (Hons), M. Int. Law

David Morgan was appointed to the Board in December 2014 and served as Chair from March 2016 to December 2017.

David has previously served as a diplomat and represented Australia in international trade and environment organisations, and was the visiting fellow at the University of Melbourne from 2004 to 2009. David is chair of the Emorgo Foundation, a director of the Victorian Bridge Association, and a councilor of the Australian Bridge Federation. He received a kidney from his father in 1989.

CELEBRATING OUR 50th ANNIVERSARY

Kidney Health Australia is proud to have supported and worked with the kidney community since 1968.

To celebrate our 50 year anniversary, our Patron, His Excellency the Governor-General Sir Peter Cosgrove, and Lady Lynne Cosgrove, graciously hosted 80 people from our kidney community at Admiralty House in Sydney on 3 September 2018.

We used this milestone to share messages of gratitude to our network and thank them for their support and commitment in continuing to help fight kidney disease across Australia. It was also the perfect occasion to present two significant community awards: The Kincaid-Smith Medal to acknowledge an outstanding contribution to kidney disease research and the Mark Colvin Scholarship in partnership with the ABC.

The Kincaid-Smith Medal was created in 1994 in honour of Priscilla Kincaid-Smith, a pioneering nephrologist and founding member of our organisation. The Kincaid-Smith Medal is the highest accolade awarded to an Australian citizen or resident in recognition of their outstanding clinical and scientific achievement in research into the treatment of diseases of the kidney and urinary tract.

We were proud to announce Dr Carmel Hawley as the 2018 medallist, in acknowledgement of her contribution to research as the principal driver of the Australasian Kidney Trials Network. Carmel's work will improve the care and treatment for patients with kidney disease by refining the evidence base of care, quality of life and outcomes.

The inaugural Mark Colvin Scholarship was developed in partnership with the ABC. Mark was a highly regarded journalist and former Australian correspondent, and a committed advocate for kidney health due to his personal experience with dialysis and as a transplant recipient. Sadly, Mark died in May 2017 from complications related to kidney disease.

Entry-level journalists or those from non-traditional journalism backgrounds, who could demonstrate a passion for quality reporting and excellence in storytelling, were encouraged to apply for the scholarship.

We were pleased to award Alex Tighe the Mark Colvin Scholarship for 2018. Alex, aged 23, has worked in community media as a writer, editor and radio producer. Alex knows too well the effect kidney disease can have on people's lives, as his mother is currently living with the disease.

Dr Carmel Hawley, Kincaid-Smith Medal recipient.





Melbourne Royal Botanic Gardens.

As a part of his 12 month scholarship, Alex will be mentored by leading ABC journalists on the skills needed to report across multiple media platforms and have the opportunity to work with ABC journalists on an in-depth story.

As we look to the next 50 years, we recognise the incredible achievements of our kidney community and the many ways in which Australians have been helped and supported by this organisation. But we recognise that there is much more to be done to alleviate the burden of kidney disease at all stages.



“ Whilst there has been enormous progress made since 1968, 1.7 million Australians are affected by kidney disease, and 1.5 million are not aware of it. For all the education, advocacy, research and support, kidney disease continues to be a silent killer. Ninety per cent of kidney function can be lost without any symptoms. Picking up any disease late is never a good thing.”
 - Sir Peter Cosgrove

(L-R) Michelle Guthrie, former ABC CEO; Nick McKenzie; Prof. Carol Pollock, Board Chair, Kidney Health Australia; His Excellency the Governor-General Sir Peter Cosgrove; Lady Lynne Cosgrove; Dr Lisa Murphy, GM - Prevention and Advocacy, Kidney Health Australia; Alex Tighe, Mark Colvin Scholarship recipient; Anita Tighe.

STRATEGY

NATIONAL STRATEGIC ACTION PLAN

The Federal Government commissioned Kidney Health Australia to develop a National Strategic Action Plan for Kidney Disease in 2018. The Action Plan will be released this year and contains guidance, goals and specific actions we can take to improve Kidney Disease care.

The Action Plan was commissioned in recognition of the significant and growing impact of kidney disease on the health and wellbeing of Australians as well as the economic impact on society.

1.7 million people in Australia are currently living with chronic kidney disease, including more than 11,000 people who have received a kidney transplant and over 12,000 who undertake dialysis treatment. The Action Plan will be the first coordinated Federal Government strategy to combat kidney disease.

The Action Plan has been guided by an expert Advisory Group and the Kidney Health Australia National Consumer Council and has been developed based on extensive consultation with the Australian kidney community including people with kidney disease and their carers and family, health professionals, researchers, government representatives and policy makers and non-government organisations.

The consultation process included:

- a roundtable with over 50 participants
- an online public consumer survey to which over 2,500 stakeholders provided input and comment
- over 30 discrete interviews with individuals, organisations and the government
- a public consultation on the final draft of the Action Plan.

Using the information gathered, we identified three major priority areas for action:

1. Prevention, Detection and Education.
2. Optimal Care and Support.
3. Research and Data.

Under each of these major priority areas are a number of recommendations for action including specific tasks relating to kidney transplantation, and kidney disease in Aboriginal and Torres Strait Islander peoples.

The Action Plan will be submitted to the Department of Health at the end of June 2019.

We believe the Action Plan will provide direction and opportunities to build upon our valuable work to promote good kidney health. We will share the Action Plan with the kidney community once it is ready for wider public distribution.



'ON COUNTRY' DIALYSIS

Kidney Health Australia was instrumental in the Federal Government's decision to fund a Medicare Benefit Schedule (MBS) item which will enable 'on country' dialysis for Australians living with end-stage kidney disease in very remote areas.

This significant achievement for the kidney community is the result of the MBS Review Taskforce Renal Clinical Committee Report's recommendation in 2017.

This announcement is particularly important in the Aboriginal and Torres Strait Islander communities where the rates of kidney disease are higher than any other community in Australia:

- in remote and very remote areas of Australia, the incidence of end-stage kidney disease for Aboriginal and Torres Strait Islander Australians is up to 20 times higher than amongst non-Indigenous Australians
- 78% of patients in remote areas with end-stage kidney disease have to relocate, compared with 39% of those who live in rural areas and 15% of urban Indigenous patients with end-stage kidney disease
- amongst Aboriginal and Torres Strait Islander Australians, the heaviest disease burden impacts on people living in very remote (36.7%) and remote (27.6%) regions.

We welcome the Federal Government's decision and will continue to advocate for changes that will improve and save the lives of all Australians affected by kidney disease.

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

PREVENTION AND DETECTION

For 50 years, Kidney Health Australia has been helping Australians understand the importance of good kidney health through our education and community outreach programs.

PRIMARY CARE EDUCATION PROGRAM

OUR IMPACT **45K+** REACHED THROUGH PROFESSIONAL EDUCATION

We continue to lead the way in providing world class education on detection and management of kidney disease for GPs and other health professionals. Of the 45,000 health professionals reached through our Primary Care Education Program;

- 3,701 health professionals completed our education module
- 6,250 hours of accredited face-to-face and online education was delivered to health professionals
- 27,000 health professional resources were distributed, including the well regarded guideline handbook Chronic Disease Management in General Practice and CKD GO! App.

In 2018, to complement our Primary Care Education Program, we established a new Chronic Kidney Disease Ambassador Program designed to drive behavioural change around CKD detection and management in primary care practices. During the year, we had 61 health professionals enrolled in the new program.

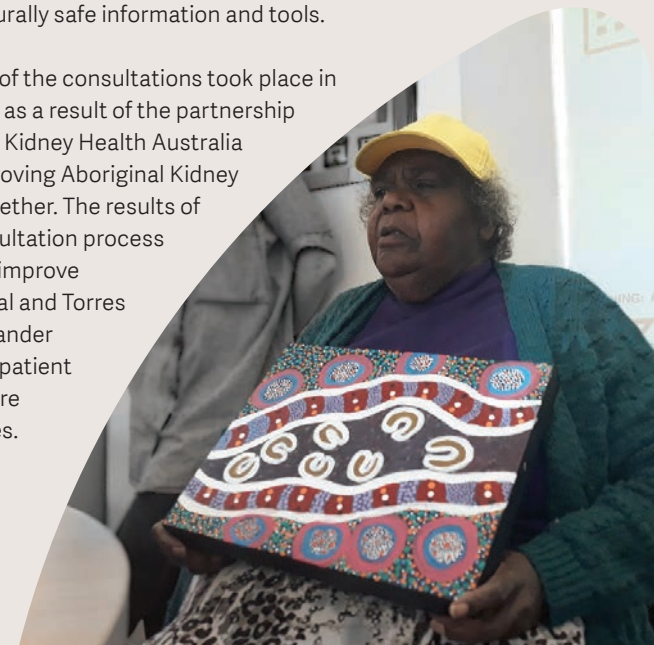
Thanks to our generous healthcare volunteers and workshop hosts who gave thousands of hours of their time and \$450,000 worth of in-kind support.

kidney.org.au/health-professionals/detect/education

KHA-CARI GUIDELINES

Clinical guidelines are critical to improving health outcomes, and the Kidney Health Australia - Caring for Australasians with Renal Impairment (KHA-CARI) guidelines have been helping clinicians care for people with kidney disease since 1999. The guidelines cover three areas: kidney disease, dialysis and transplantation. We continue to part-fund the guidelines with a grant of \$120,000 and they are managed by the KHA-CARI Steering Committee. To improve Indigenous kidney health, the Federal Government commissioned Kidney Health Australia in 2017 to undertake consultations to inform the development of KHA-CARI guidelines specifically for the management of chronic kidney disease for these communities. A total of 16 consultations will be conducted to determine how we should best translate the new guidelines into culturally safe information and tools.

The first of the consultations took place in Adelaide as a result of the partnership between Kidney Health Australia and Improving Aboriginal Kidney Care Together. The results of the consultation process will help improve Aboriginal and Torres Strait Islander people's patient healthcare outcomes.



Patient Inawinytji.

KIDNEY HEALTH WEEK

OUR IMPACT

49M+ MEDIA REACH

4.5M+

SOCIAL MEDIA REACH

11K+ RISK TESTS COMPLETED

With 1.5 million people unaware that they are living with the early signs of kidney disease, we stepped up our efforts to raise awareness of the risk factors particularly during Kidney Health Week. The aim for the week, which ran from 5 - 11 March 2018, was to open everyone's eyes to kidney disease by raising awareness of the alarming fact that one in three people living in Australia is at increased risk.

Our message was: "Don't Be Blind To Kidney Disease" by waiting until you feel sick; find out your risk profile and, if you fall into a high-risk group, get your kidneys checked by a GP. A new online kidney risk test was launched to help people find out if they were at increased risk of kidney disease. The test continued to be promoted throughout the year and was successful in getting 11,000 people to check their kidney disease risk.



Kidney Health Australia would like to thank everyone who supported the week by holding events in their local communities and our wonderful ambassadors for sharing their personal stories with kidney disease to help spread the message even further:

- Frances Peters-Little, daughter of late Jimmy Little, who passed away with kidney disease
- Phil Davis, AFL player for GWS Giants, who nearly lost a kidney after being injured during a game, putting him at increased risk of kidney disease
- Tom Lonergan, retired AFL player for Geelong Cats, who endured an emergency life-saving operation to remove his right kidney, resulting from an acute kidney injury whilst playing football
- Nick McKenzie, son of late Mark Colvin, ABC journalist who passed away with kidney disease in 2017.

COMMUNITY AWARENESS

OUR IMPACT

416K+

WEBSITE VISITS

500K+

RESOURCES DISTRIBUTED

As the peak body for the kidney community, we continue to be the trusted provider of accurate, reliable and easy to understand information on kidney health. Our website continues to be the key channel for information, with 416,900 visits over the year, and 1,176,200 unique page views.

We distributed over 500,000 resources online, in workshops and via our Kidney Helpline. These included over 50 fact sheets, books and videos covering a variety of topics from keeping your kidneys healthy, treatment options for kidney disease including transplantation, to living well with kidney disease. Our resources have been translated into 19 different languages to ensure adequate access for everyone in the kidney community.

Kidney Health Australia remains committed to supporting people living with kidney disease and will continue to raise vital funds needed for research into early detection and prevention.

SUPPORT

OUR KIDNEY **COMMUNITY**

OUR IMPACT **42** PEER SUPPORT NETWORKS AUSTRALIA-WIDE

Local social groups provide valuable support to people at any stage of kidney disease, their loved ones and carers. We facilitated 42 community social group meetings nationally in 2018 to ensure people with kidney disease can access support and information no matter where they live. While endorsed by Kidney Health Australia, these groups operate autonomously at the local level.

Kidney Health Australia's National Consumer Council and State Consumer Groups in Queensland and South Australia met quarterly throughout the year, providing valuable consumer feedback to the organisation and offering support to these groups. We look forward to working with them more closely in 2019.

kidney.org.au/connect/support-groups/community-support

KIDNEY **HELPLINE**

OUR IMPACT **1.8K+** SUPPORTED THROUGH HELPLINE

The Kidney Helpline continues to offer free information, support, referrals and advice to patients, their families and health professionals. In 2018, the Kidney Helpline helped over 1,800 people living with kidney disease and their family members.

Callers ranged from people with kidney disease (42% of callers), family members and friends (28%), students, researchers, and other organisations (11%), and health professionals (8%). The helpline continues to be a vital first point of contact for our community and we aim to expand and enhance this service.



Kidney Helpline

Freecall: 1800 454 363

kidneyhelpline@kidney.org.au

THE **BIG RED KIDNEY BUS**

OUR IMPACT

1K+

PATIENTS ENJOY FAMILY HOLIDAYS WITH REMOTE DIALYSIS

Over 1,000 patients across New South Wales and Victoria used the Big Red Kidney Bus in 2018. The Big Red Kidney Bus travelled to 14 popular tourist destinations, offering people on dialysis the chance to enjoy a much-needed break, whilst still providing this essential service.

We wish to thank our partners, Monash Health and Royal North Shore Hospital, who provide the clinical care for people dialysing on the buses. We also thank our many funding partners, individuals and communities who have assisted The Big Red Kidney Buses including Rotary Club of Croydon, Bus Association Victoria and Dyson Group.



To book your place on the bus, visit kidney.org.au/bus

Help keep this free mobile dialysis unit running by making a donation at kidney.org.au/donate

Patient Ian with nurse Glenis from Monash Health.



William and Melanie, first tenants at our Adelaide Emorgo Kidney Transplant House.

KIDNEY TRANSPLANT HOUSES

OUR IMPACT
40 FAMILIES GIVEN
ACCOMMODATION
299 DAYS AVERAGE
OCCUPANCY

Our transplant houses provided 40 patients free comfortable, quality accommodation across Perth, Melbourne and Adelaide in 2018, with the houses being occupied on average for 299 days out of the year. This was an exciting year for our kidney transplant housing program as we launched in Adelaide in October.

Our new Adelaide Emorgo Kidney Transplant House has provided accommodation for five patients and their families since the end of May. Kidney Transplant Houses offer the opportunity to keep families together while easing their financial and emotional burden. This would not be possible without the continued generosity of the Emorgo Foundation.



KIDNEY YOUTH PROGRAM



For the estimated 700 young people living in Australia with kidney disease, moving from paediatric care to adult healthcare settings is a difficult transition.

With funding provided by the Federal Government, our new national Kidney Youth Program is undertaking a national consultation process to design peer support groups and education activities that will help those aged 18 to 24 living with kidney disease get the support they need to maintain independence and pursue study and employment opportunities. We will share the findings of our national consultation with the kidney community once they become available.



KIDNEY KIDS CAMP

OUR IMPACT 100 HAPPY FACES

In 2018, over 100 children living with kidney disease and their siblings aged 7 to 17 participated in our annual Kidney Kids Camp, held at Runaway Bay Sports Super Centre in Queensland. The children spent four fun-filled days making new friends, building their confidence and creating lasting memories. This year's camp theme was Kidney Health Games in commemoration of the 2018 Gold Coast Commonwealth Games.

We thank our 90 volunteers and medical professionals for providing a safe environment for children with often complex medical needs.



Thanks to the generosity of our kidney community for raising funds to ensure we can continue to provide essential support to people living with kidney disease, boost our research efforts and increase public awareness.

FUNDRAISING

BIG RED **KIDNEY WALK**

OUR IMPACT
5K+
PARTICIPATED
\$331K+
RAISED

Since 1982, we have been hosting our annual fundraising charity walk that unites thousands of people across Australia whose lives have been affected by kidney disease, and allows the community to show their support.

In 2018, we had our largest participation to date with 5,096 participants walking in Brisbane, Sydney, Melbourne, Perth and Adelaide in support of those living with kidney disease. Some walk in honour of a loved one or work in the sector and are passionate about supporting kidney health.

Many walk participants are personally affected by kidney disease. Troy is one of these people. A regular at the Big Red Kidney Walk in Brisbane, Troy and 21 of his peers raised over \$3,000 for those living with kidney disease this year. Since being diagnosed with kidney disease in 2001, Troy has become a local advocate for the importance of kidney awareness and early detection. A big thank you to everyone who raised vital funds for the kidney community this year.

“We take on this challenge to help people like me get the support they need to achieve their goals and to get out awareness of kidney disease to the general public.”

- Troy



Register to take part in the next Big Red Kidney Walk at kidney.org.au/walk

KIDNEY KAR RALLY

OUR IMPACT
\$544K+
RAISED FOR
YOUNG PEOPLE

The Kidney Kar Rally has been supporting kids and youth with kidney disease for over 30 years and continues to raise funds and awareness of kidney disease in the local communities it travels through. The rally is not a race but a test of skills. It's for those who want to share with mates the adventure and experience of driving thousands of kilometres across the beautiful and rugged Australian countryside, with the ambition to change the lives of kids with kidney disease.

Team Xplant led by John was this year's top fundraisers raising over \$45,000. The cause is a personal one for John, as in 2008 he was diagnosed with kidney failure. Thankfully, he received a transplant from his wife in 2009 but the two weeks on dialysis leading up to the transplant have stayed with him. John says that the reason he has participated every year since 2010 is that he doesn't know how kids and youth get by having to go on dialysis three times a week for five hours a day.

A big thank you to everyone who participated in this year's event.

Register to take part in the next Kidney Kar Rally at kidneykarrally.org.au



"The kids are so resilient, they just amaze me."
- John, Team Xplant

*Kidney Health Australia
awarded \$250,000 in
research grants during 2018.*

RESEARCH

OUR IMPACT

\$250K AWARDED TO **5** NEW RESEARCH GRANTS TO IMPROVE QUALITY AND DURATION OF LIFE FOR PEOPLE WITH KIDNEY DISEASE

Over the past 50 years, we have raised over \$30 million towards kidney research, contributing to the vital work of researchers in Australia and internationally. After an extensive period of consultation with the kidney community and guided by the Kidney Health Australia Research Advisory Group, we have identified the three key research areas below:

1. Improving quality and duration of life for those living with chronic kidney disease.
2. Making kidney transplants last longer.
3. Preventing the progression of chronic kidney disease.

During the next three years, we will award grants to support each of the research areas identified. This year, at an event hosted by KPMG, we presented \$250,000 in grants to five successful applicants who are focused on improving the quality and duration of life for those living with the disease. The successful research grant recipients are listed on the following page.



PJ Hartshorne, Kidney Health Australia Board member.

This year we provided a \$75,000 grant to the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA), to go towards its general operating costs. ANZDATA underpins crucial research and policy development activities across Australia and New Zealand, and is one of the world's most comprehensive and valued renal registries. The registry has contributed greatly to knowledge, planning and best practice in clinical care over many years.

Each year, we award \$8,000 in prizes at the Australia and New Zealand Society of Nephrology Annual Scientific Meeting (ANZSN ASM), and the Transplant Society of Australia and New Zealand scientific meeting. This year, the first prize of \$5,000 was awarded to Dr Philip Clayton from the Royal Adelaide Hospital for the best clinical nephrology presentation.

BASIC SCIENCE

Prof. Jonathan Gleadle, Flinders University, South Australia

Roles for microRNAs in compensatory renal hypertrophy.

This project will use novel genetic tools to identify key components that lead to healthy kidney growth.



Twanny Farrugia, kidney transplant recipient and Kidney Health Australia Lifetime member.



Dr Lisa Murphy, GM – Prevention and Advocacy, Kidney Health Australia with Dr Melissa Little, Murdoch Children's Research Institute.

CLINICAL

A/Prof. Rachael Morton, University of Sydney

*Symptom monitoring with Feedback Trial (SWIFT) pilot:
A feasibility and acceptability study of ANZDATA E-PROMs data capture and feedback.*

SWIFT aims to improve quality of life and survival rates of those living with CKD by focussing on symptom management and encouraging communication between doctors and their patients.

Dr Louise Purtell, QUT

The REPOSE study (Randomised Evaluation of the Provision of a Sleep intervention in End-stage kidney disease).

An individual sleep plan will be developed for each CKD patient to improve quality of life and reduce health problems associated with a lack of sleep.



(L-R) Prof. Angela Webster, A/Prof. Rachael Morton, Prof. Jonathan Gleadle, Dr Louise Purtell, Prof. David Castle.

PSYCHOSOCIAL

Prof. David Castle, St Vincent's Hospital, Melbourne

A randomised controlled trial of psychosocial intervention to improve health outcomes in people with kidney disease.

The Kidney Optimal Health Program provides one-on-one individual support about stress and vulnerability and its impact on health and well-being for those living with CKD.

Prof. Angela Webster, University of Sydney

SUCCESS: Supporting culturally diverse adults with CKD to engage in shared decision making successfully (Phase II).

Dialysis patients will use an app to make changes to their health that will improve their health and quality of life, and reduce their need for unscheduled or emergency health care visits.

FINANCES

Kidney Health Australia generated a revenue surplus in 2018.

We achieved an operating surplus of \$825,934 for the year, compared with an operating loss of \$455,306 in 2017. This is a \$1.3m improvement which was driven by revenue growth and key cost containment. Our focus on building strong stewarded donor relationships yielded significant growth in revenue from bequests and other charitable income (increased by \$2.1m to \$5.5m).

In addition, Kidney Health Australia was the recipient of \$1.4m of grants from the Federal Government for the development of a National Strategic Action Plan for Kidney Disease and assisting youth affected by kidney disease as they transition from paediatric to adult care environments. The grant was also put towards the development of culturally appropriate care guidelines for Aboriginal and Torres Strait Islanders suffering from kidney disease.

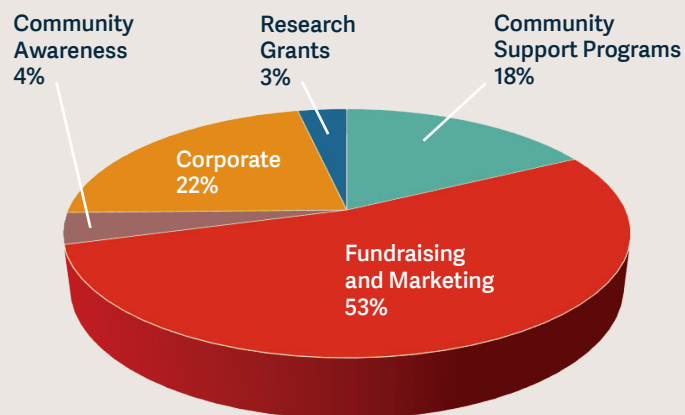
Net cash flows from operating activities increased by \$2.6m from the previous year due to a combination of increased revenue inflows and \$0.77m of savings in operating expenditure. We invested in important infrastructure and assets including a new transplant house in Adelaide for use by kidney transplant recipients and their families as well as improvements in capability, compliance and security of information technology systems.

As noted, Kidney Health Australia also made an important investment in kidney-related research via the award of \$250,000 worth of research grants.

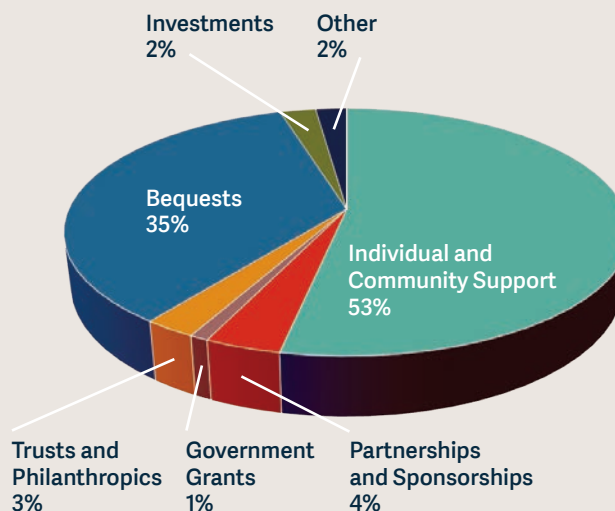
Our plan is to develop a strategy that will position us for longer-term growth and financial sustainability, which will include sustainable revenue streams to enable delivery of valued services and support to the kidney community. We would like to thank our supporters and benefactors for their generosity and ongoing contributions to improving the lives of those affected by kidney disease. There is still more work to be done and we ask for your ongoing support.

For further information, you can view our complete financial statements on our website: Kidney.org.au/about-us/annual-reports

2018 EXPENSES



2018 REVENUE



FINANCIAL POSITION

As at 31 December 2018	2018 \$	2017 \$
Assets		
Total current assets	2,532,324	1,014,591
Total non-current assets	4,254,668	4,457,162
Total Assets	6,786,992	5,471,753
Liabilities		
Total current liabilities	2,283,470	1,594,017
Total non-current liabilities	278,569	305,732
Total liabilities	2,562,039	1,899,749
Net assets	4,224,953	3,572,004
Equity		
Total equity	4,224,953	3,572,004

THE PEOPLE WE'D LIKE TO THANK

BEQUESTS REALISED IN 2018

We acknowledge and remember the following generous donors whose bequests were realised in 2018.

- Estate of Colin Archer
- Estate of Rosemary Aylett
- Estate of Jack Bannister
- Estate of Moya Bray
- Estate of Donald Bull
- Estate of Elissa Bullen
- Estate of Kenneth Douglas
- Estate of Lois Ferguson
- Estate of Alice Hardaker
- Estate of Atholie Houghton
- Estate of Peter Joynson
- Estate of Peter Krafel
- Estate of Jack Lang
- Estate of Doreen Letcher
- Estate of Carol Madden
- Estate of Freda McCullough
- Estate of Margaret McGrow
- Estate of Nigel Miller
- Estate of Margaret Newton
- Estate of Zula Nittim
- Estate of Ronald O'Donnell
- Estate of Miriam Philipp
- Estate of Kathleen Rankin
- Estate of Colin Renaud
- Estate of Jean Rentoul
- Estate of Dulcie Roesler
- Estate of Annie Shepherd
- Estate of Reginald Stanley
- Estate of Jeanette Stuart
- Estate of Dorothy Symblett

TRUSTS FOUNDATIONS AND GRANTS

We are proud of our enduring connections with organisations that are committed to helping people affected by kidney disease. We thank you for your generosity.

- AMP Foundation
- AON Charitable Foundation
- Aurizon Community Giving Fund
- Bofac Foundation
- Centenary Foundation - Sylvia Richardson
- CMV Staff Charitable Foundation
- Dorothy E Brown Trust
- Duncan Family Trust
- Emorgo Foundation
- Fay Fuller Foundation
- Flight Centre Foundation
- Global Aid Foundation
- H & H Cohney Foundation
- Health Services Charitable Gifts Board
- Lord Mayor's Charitable Foundation
- McDonald Jones Homes Charitable Foundation
- Pethard Tarax Charitable Trust
- Phillips Family Foundation
- Queensland Community Foundation
- Randall Foundation
- Rees Family Foundation
- State Trustees Australia Foundation
- The Barbara Luree Parker Foundation
- The Eirene Lucas Foundation
- The Freemasons Foundation
- The Grenda Foundation
- The Harry F Carter Charitable Trust
- The Isabel & John Gilbertson Charitable Trust
- The Miller Foundation
- The Slome-Topol-Rosen Family Charitable Trust
- The Stan Perron Charitable Trust
- The Steve McKerihan Charitable Trust
- The Sunraysia Foundation
- The William Angliss (Queensland) Charitable Fund
- The William Angliss (Victoria) Charitable Fund
- Thomas Hare Investments Ltd.

MAJOR DONATIONS

We sincerely thank the following major donors for their generous support in 2018.

- Lenore Adamson
- Nicholas Aitken
- Graham Anderson
- Rita Andre
- John Aston
- Ray Aurisch
- Geoffrey Baker
- Justin Bates
- Judy Becher
- Judith Berenger
- Tessa Boyer
- June Bramich
- Neville Broome
- Russell Brothers
- Sophie Cachia
- Central Coast
Kidney Support Group
- Stan Chegwidden
- Barbara Cimetta
- Wendy Coghill
- RG & CL Corrigan
- Anna Cowen
- Jennifer Cranwell
- Liz Criniti
- Paul Cross
- Sushoma David
- Peter Despard
- Graham Diggins
- Allan Diplock
- Poppy Dowsett
- John Eastment
- Melville & Suzanne Edwards
- Jehan Eltigi
- Brenda Every
- Henry Foster
- Jenny Frith
- Audrey Fuhrer
- Judith Galloway
- Michael Gilmour
- Margery Gist
- James Glass
- Annie Gregg
- Peter Griffiths & Family
- Peter Haeusler
- Ian Hayward
- Chalana Hewage
- Katy Honig
- Jessica Hore
- Dorothy Howse
- Albert Hung
- Gayle Hutchinson
- Thora Ilett
- Fulbert James
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- Mark Mathiesen
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- John McMaster
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- Trevor Saunders
- Patricia Scally
- Alison Shillington
- Peter Siminton
- June Smith
- Merelyn Southwell-Keely
- Conrad Stephenson
- Steven Stevens
- Harry Tamvakeras
- Teck Ming Tang
- John Toomey
- Bruce Verity
- Amber Vincent
- Linda Warszewski
- Barney Williamson
- Richard Yue Hong Yu
- Ahsan Zafar
- Beryl Zakharov

VOLUNTEERS

We gratefully acknowledge all of our valuable volunteers who give their time so generously to support our fundraising, support and awareness raising activities.

For more information email touchvolunteering@kidney.org.au

PRIMARY CARE EDUCATION VOLUNTEERS

Our Primary Education program simply would not exist without the dedicated nephrologists, GPs, renal nurses, Primary Care nurses and educators who make up PEAK. Nephrologists and renal nurses also volunteer their time to present educational workshops to primary care health professionals and volunteers also assist the Kidney Health Australia education team with administrative tasks.

PEAK MEMBERS IN 2018

- Prof. David Johnson (chair)
- Dr Chris Bollen
- Ms Kathy Godwin
- Ms Barbara Harvie
- A/Prof. Shilpa Jesudason
- A/Prof. Ivor Katz
- Prof. Robyn Langham
- A/Prof. Craig Nelson
- Dr Richard Phoon
- Prof. Kevan Polkinghorne
- Dr Angus Ritchie
- Dr John Saunders
- Ms Wendy Shepherdley
- Prof. Tim Usherwood
- Dr Sheena Wilmot

PRIMARY CARE VOLUNTEER PRESENTERS AND CONTENT REVIEWERS

- Dr Jobert Angelo
- Ms Cherie Arnold
- Dr Sunil Badve
- Dr Richard Baer
- Dr Nicholas Barraclough
- Dr Chris Bollen
- Prof. Neil Boudville
- Ms Leanne Brown
- Dr Shafiq Chowdhury
- Dr James Collett
- Ms Catherine Connor
- Ms Trish Coutts
- Ms Jovitha Deborah
- Ms Laurel Dodd
- Ms Katrina Duff
- Dr Margaret Fraenkel
- Dr Ian Fraser
- Mr Robert Gardos
- Dr Pratish George
- Ms Ria Gilham
- Ms Denija Grzunov
- Dr Alok Gupta
- Dr Imad Haloob
- Dr Helen Healey
- Ms Dianne Holland
- Dr Jane Holt
- A/Prof. Shilpa Jesudason
- Dr David Johnson
- Dr Clare Jones
- Dr Julie Jones
- Dr John Katsoulis
- A/Prof. Ivor Katz
- Prof. Peter Kerr
- Dr Namrata Khanal
- Dr Hemant Kulkarni
- Dr Vincent Lee
- Dr Kathy Mac
- Ms Catherine Machejefski
- Dr Pradeep Mishra
- Dr Manohar Mogulla
- Dr Harry Moody
- Ms Elizabeth Mulrooney
- Ms Susan Mwangi
- Dr Kushma Nand
- Dr Hari Nandakhoban
- Dr Genie Pedagogos
- Ms Rochelle Pitt
- Ms Sandra Porter
- Ms Debbie Pugh
- A/Prof. Gopi Rangan
- A/Prof. Matthew Roberts
- Dr Veronica Rogers
- Dr David Rutherford
- Dr John Saunders
- Dr Rob Shaw
- Dr Yvonne Shen
- Dr Richard Singer
- Dr Brian Siva
- Ms Tanya Smonologov
- Ms Mikki Smyth
- Ms Cassandra Stone
- Dr Suda Swaminathan
- Dr Caitlin Sum
- Dr Girish Talaulikar
- Dr Edward Tai
- Prof. Mark Thomas
- Ms Glenys Tulett
- Mr Graeme Turner
- Mr Martin Wilkinson
- Ms Kylie Wyndham

EDUCATION VOLUNTEERS

- Mr Graeme Blyth
- Ms Maddie Rose

KHA-CARI STEERING COMMITTEE

We thank the current members of the KHA-CARI Steering Committee, who together oversee development and promotion of the KHA-CARI guidelines.

CHAIR

- Prof. Suetonia Palmer

MEMBERS

- Prof. Neil Boudville
- Prof. Jonathan Craig
- Ms Debbie Fortnum
- A/Prof. Shilpa Jesudason
- Dr Kelly Lambert
- A/Prof. David Mudge
- A/Prof. Kevan Polkinghorne
- Dr Emily See
- A/Prof. Nigel Toussaint
- A/Prof. Rachael Walker

NATIONAL CONSUMER COUNCIL

Our National Consumer Council, South Australian and Queensland Consumer Groups were established as a formal pathway for people living with kidney disease to highlight the issues and opportunities they are experiencing, and to provide Kidney Health Australia with feedback on a wide range of topics. We are immensely grateful to all committee members for their valuable contribution to Kidney Health Australia in 2018.

NATIONAL CONSUMER COUNCIL

- Paolo Cardelli
- Martin Chambers
- Greg Collette
- Dale Creely
- John Griffiths
- Bill Handke
- Dr Brooke Huuskes
- Shaun Johnson
- Mason Little
- Luke Macauley
- Barry Mackinnon
- Fabian Marsden
- Wayne McGlone
- David Morgan
- Shyamsundar Muthuramalingam
- Tamara Paget
- Dr Chirag Patel
- Cilla Preece
- Jan Watson
- Peter Williams

SOUTH AUSTRALIA CONSUMER GROUP

- Paolo Cardelli (Chair)
- Linda Christy
- Jacquie Dennis
- Rama Mohan
- David Roberts
- Joy Roberts
- Jason Size

QUEENSLAND CONSUMER GROUP

- Phil Carswell
- Martin Chambers
- Helen Mees
- Troy Ravenscroft
- Maurice Serico
- Amber Williamson

PHARMACEUTICAL PARTNERS

Pharmaceutical sponsorship in the form of unrestricted educational grants underpins our patient and health professional education programs. We thank the following pharmaceutical partners for their generous support.

- Amgen Australia Pty Ltd
- Baxter Healthcare Pty Ltd
- Boehringer Ingelheim / Lilly
- Otsuka Australia Pharmaceutical Pty Ltd
- Roche Products Pty Ltd

KHA RESEARCH ADVISORY GROUP

We thank the members of the KHA Research Advisory Group, who together oversee the Kidney Health Australia strategic direction and agenda.

- Prof. Steve Chadban
- Mr Peter Jon Hartshorne
- A/Prof. Shilpa Jesudason
- Prof. Richard Kitching
- Dr Lisa Murphy (GM Prevention and Advocacy)
- Prof. Carol Pollock
- Dr Emma Tinning (ANZSN/KHA Research Project Officer)
- Mr Peter Williams (consumer)

KIDNEY KIDS CAMP

We thank the following health professionals for their generous support in 2018.

CAMP DOCTOR

- Matthew Sypek, Royal Melbourne Hospital
- Corey Anderson, Monash Children's Hospital
- Aimee Crawford, Lady Cilento Children's Hospital
- Brendan Cusack, Royal Children's Hospital
- Melisa Dzankovic, Monash Children's Hospital
- Fiona Gilbert, Women's and Children's Hospital Adelaide
- Cherie Golaw, Royal Children's Hospital
- Emilie Hay, Royal Children's Hospital
- Yogarani Jeyakumar, Monash Children's Hospital
- Joanne Jones, Lady Cilento Children's Hospital
- Kirsty Nilsen, Women's and Children's Hospital Adelaide
- Ky-Lee Pirone, Women's and Children's Hospital Adelaide
- Loren Shaw, Royal Children's Hospital

YARNING KIDNEYS ADVISORY GROUP

We thank the following advisory group for their generous support in 2018.

CHAIR

- A/Prof. Shilpa Jesudason – Clinical Director
Kidney Health Australia and Staff Specialist Nephrologist
Royal Adelaide Hospital

MEMBERS

- Prof. Alan Cass, Menzies School of Health Research
- Dr Martin Howell, KHA-CARI Office
- Dr Jaquelyne Hughes, Menzies School of Health Research
- Dr Janet Kelly, The University of Adelaide
- Dr Odette Pearson, South Australian Health and Medical Research Institute (SAHMRI)
- Ms Rochelle Pitt, Apunipima Cape York Health Council Limited
- Ms Jess Styles, National Aboriginal Community Controlled Health Organisation (NACCHO)

CLINICAL YOUTH ADVISORY GROUP

We thank the following advisory group for their generous support in 2018.

CHAIR

- A/Prof. Shilpa Jesudason – Clinical Director
Kidney Health Australia and Staff Specialist Nephrologist
Royal Adelaide Hospital

MEMBERS

- Dr Thomas Forbes - Paediatric Nephrologist,
Royal Children's Hospital
- Dr Anna Francis - Paediatric Nephrologist,
Lady Cilento Children's Hospital
- Dr Matthew Jose - Nephrologist, Royal Hobart Hospital
- Dr Sean Kennedy - Paediatric Nephrologist,
Sydney Children's Hospital
- Dr Nick Larkins - Paediatric Nephrologist,
Perth Children's Hospital
- Dr Marie Ludlow – General Manager Community Programs,
Kidney Health Australia

NATIONAL STRATEGIC ACTION PLAN ADVISORY GROUP

We thank the following advisory group for their generous support in 2018.

CHAIR

- A/Prof. Shilpa Jesudason – Clinical Director
Kidney Health Australia and Staff Specialist Nephrologist
Royal Adelaide Hospital

MEMBERS

- Karen Booth - President,
Australian Primary Health Care Nurses Association
- Fiona Donnelly - President, Renal Society Australasia
- Chris Forbes - CEO, Kidney Health Australia
- Prof. Kirsten Howard - Health Economist
- Prof. David Johnson - Nephrologist
- Prof. Peter Kerr - Nephrologist
- A/Prof. Duncan Mortimer - Health Economist
- David Parker - Consumer, Kidney Health Australia
Board Member
- Prof. Carol Pollock - Nephrologist, Kidney Health Australia
Board Chair
- Prof. Tim Usherwood - General Practitioner

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WITH US.

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FUNDRAISING**
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US TO DELIVER
OUR VITAL PROGRAMS
AND SERVICES.

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