

2016
Annual Review



Our Vision

To save and improve
the lives of Australians
affected by
kidney disease.

Our Mission

To promote good
kidney health through
education, advocacy,
research and support.

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A message from the Chair



Kidney Health Australia represents people like me—people whose lives have been changed by kidney disease. KHA provides support, shares knowledge and information, works to influence government and health policy, and offers a voice for patients and their carers and families. For almost 50 years it has also funded research into the causes of kidney disease and treatments for people with or at risk of kidney failure.

Our business priorities in 2016 focused on:

- increasing support to our kidney community increasing community and stakeholder engagement
- providing educational content for patients, carers, and health professionals world-wide
- committing to research including through the Priscilla Kincaid-Smith Kidney Research Foundation
- continuously building revenue streams.

The need for advocacy and support remains pressing. There have been many successes in reducing the incidence and impacts of other leading causes of death, but the number of people with kidney disease continues to increase. More people are on dialysis, which imposes a huge burden on the lives of patients and their families and increases the amount of taxpayer funds spent on healthcare. Major improvements in the wellbeing of people with kidney disease remain elusive.

KHA continues to provide services designed to make a difference for people with kidney disease. Among these services are our Big Red Kidney Bus, which enables people on dialysis to go on holiday, our Kidney Kids Camp, which offers a break for children with kidney disease and their families, and our transplant housing program, which provides accommodation for people from rural and regional Australia who are having a transplant or other treatment. Our information services and educational materials are widely used by patients and their families, GPs, nurses and other clinical staff.

The year 2016 was a time of change for us. We farewelled Anne Wilson and welcomed Mikaela Stafrace as new CEO. Under Anne's leadership we developed our advocacy role, expanded our educational offering, and increased the number and extent of services provided. Mikaela has already had an impact, identifying new opportunities and bringing with her an enthusiasm that springs from her knowledge of kidney disease's effects on families. The board has also charged Mikaela with improving the security of KHA's funding and implementing a new strategic alignment which focuses on building communities of people with shared experience of kidney disease.

KHA is a lean organisation. We remain independent of government and are indebted to the Australian community, corporate Australia, the philanthropic sector and the pharmaceutical industry for their loyal and generous support of our work.

I thank my fellow directors for their continuing support and especially note the contribution of my predecessor, Vin Harink, during his six years chairing the board.

David Morgan
Chair

A message from the CEO



Since joining Kidney Health Australia in September 2016 I have been overwhelmed by the generosity, tenacity, courage and humour shown by people living with kidney disease and their families. As I travel around Australia listening to people affected by the disease, I am struck by the disease's impact.

Participation in a regime of renal replacement therapy—whether it takes the form of various modes of dialysis or transplantation—is costly and often exhausting, involving travel, employment dislocation, income disruption, and reliance on others for help. Not only is the patient affected: the disease imposes a heavy burden on the families of patients.

It is against this backdrop that we are inspired to stay true to our vision—helping people who are affected by kidney disease. In the past few months we have been asking ourselves what more we can do to help and what we need to be as an organisation in order to be valuable to people living with kidney disease. The feedback has been strong: we need to be advocates; we need to speak for those who have no voice; and we need to build communities in which people sharing a common experience can come together to provide support for their peers.

To that end we have introduced a new operating model consisting of three simple areas of practice—building a community, engaging the public, and facilitating the spread of clinical

expertise. Overlying all that we do is an essential recognition of the burden of kidney disease among Aboriginal and Torres Strait Islander peoples.

Building a community of peers with experience of kidney disease. Across Australia we plan to build grass-roots communities that bring people together online and face to face, creating a community that connects consumers with each other and with existing community resources. KHA will work to develop diversionary therapy activities in hospitals and provide resource materials in GP clinics and specialist outpatient settings. We want to encourage the sharing of information and to foster comradeship. Peer support is a crucial plank of our community, as are our website and social media capacity.

Engaging the public in supporting people suffering from kidney disease and their families. Getting the right message to the right people at the right time is an essential part of involving our community. This is more than mere 'awareness': it is about the psychological and emotional connection that converts the public from simply being aware of our brand into taking action; it is about what members of the public do next after they learn of our work and the people we support. Engagement involves using our website, social media, marketing and messaging, events and our database to send important messages throughout our kidney community and into the broader Australian community.

Facilitating the spread of clinical expertise.

This concerns the 'brains trust' of Kidney Health Australia—the people who create the clinical and other content that supplies information to our community and informs members of the broader community. These people respond to the community's need for information and policy direction. Using the engagement team, they amplify that content back into the community and ensure that our representations to government and other stakeholders are clinically accurate and appropriate. They ensure that the content we create is evidence based and complies with world best practice.

All three areas of practice will collaborate closely. A multidisciplinary team will work on every program or project, using expertise drawn from each area of practice across KHA. We are also working closely with our partners in other chronic disease fields, to share information, expertise and health-messaging practices with the aim of preventing and detecting disease much earlier in its development.

I thank the KHA board, our staff, our external stakeholders and, most importantly, those who live with kidney disease for the welcome they have extended to me and for the patience and wise advice offered to me as I have settled in.

Mikaela Stafrace
Chief Executive Officer

Board members



David Morgan (Chair)

David Morgan was appointed to the KHA board in December 2014 and became chair of the board in March 2016. He had previously served as a diplomat and represented Australia in international trade and environment organisations. Among his areas of policy experience is the development of Australia's gene technology regime. From 2004 to 2009 David was a visiting fellow at the University of Melbourne; he is also the author or co-author of books and journal articles on legal, economic and political aspects of biotechnology and other trade and environment subjects. David is chair of the Emorgo Foundation, a director of the Victorian Bridge Association and a councillor of the Australian Bridge Federation. He received a kidney from his father in 1989.



Allan Collins

Professor Allan Collins was appointed to the KHA board in December 2009 and resigned from that position in December 2016. At present he is Professor of Medicine at the University of Minnesota School of Medicine's Hennepin County Medical Center in Minneapolis. He also serves as director of the Chronic Disease Research Group of the Minneapolis Medical Research Foundation, having been for 15 years the principal investigator for the US Renal Data System Coordinating Center of the National Institutes of Health, which is the registry for kidney failure patients in the United States. In 2014 Allan started the Peer Kidney Care initiative, which produces an annual report on the 14 largest independent dialysis provider groups in the United States, accounting for 90 per cent of people on dialysis in that country.



Prof. Jonathan Craig

Professor Jonathan Craig was appointed to the KHA board in December 2011. He holds a personal chair in clinical epidemiology at the University of Sydney and is a senior staff specialist at the Children's Hospital at Westmead, course director of the clinical epidemiology program at the University of Sydney, and Associate Dean of Research in the Faculty of Medicine. An internationally recognised clinician–scientist, focusing on improving the health and wellbeing of people with chronic kidney disease (especially children and Indigenous Australians), he has received a number of awards, among them the International Distinguished Medal of the National (US) Kidney Foundation (2010). Among other things, Jonathan is a past chair of the steering group of the Cochrane Collaboration, a member of the National Health and Medical Research Council expert advisory group on NHMRC funding and the advisory group on the synthesis and translation of research evidence, and a member of the Pharmaceutical Benefits Advisory Committee and the Medicare Services Advisory Committee.

Board members



Vin Harink

Vin Harink has been a KHA director since December 2004 and was chair of the board and the Finance Committee from April 2010 to March 2016. He is the CEO of Veuve Property Group, a privately owned enterprise that develops and owns early learning centres in Australia, and a non-executive director of Altus Group Holdings Pty Ltd and subsidiaries, a traffic management group with interests in Australia and the United States. In addition to his extensive experience in funds management, Vin has more than 20 years' experience in corporate finance, mergers and acquisitions, and capital markets as a director of Austock Corporate Finance Limited, a partner with Deloitte Touche Tohmatsu, a director of Deloitte Corporate Finance Limited and a director of KPMG corporate Finance Pty Ltd. He is a member of KHA's Finance and Remuneration and Succession Planning Committees.



PJ Hartshorne

PJ (Peter Jon) Hartshorne was appointed to the KHA board in April 2008. After a six-year cadetship with McKinsey & Company, he went on to work for a number of top 100 international companies in the areas of strategy and technology enablement. He is now 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. PJ is also Chairman of Scholaris International Ltd, an international education-based software company, and Redgum Corporate Pty Ltd. He is a member of KHA's Remuneration and Succession Planning Committee and was appointed Chair of the Finance Committee in March 2016.



Graeme Holmes

Graeme Holmes was appointed to the KHA board in May 2007. He has more than 30 years' domestic and international experience in business and strategic planning and general management, industrial relations, and strategic human resource management. His involvement with charitable organisations includes 14 years with KHA and work with the Prahran Mission. Graeme is a member of KHA's Finance Committee and chairs the Remuneration and Succession Planning Committee.

Board members



Peter Mitchell

Peter Mitchell was appointed to the KHA board in May 2007. At present he is a commercial adviser to FMT Worldwide, an Australia-based software company. His career spans over 50 years in finance with the Commonwealth Bank and Perpetual Private clients; additionally, he served for seven years as a board member with Kids Help Line Australia and for three years as a board member with the Australian Lasallian (Asia/Pacific) Foundation, which supports aid and development projects designed to offer disadvantaged children an opportunity to break the cycle of poverty. Peter was also a long-serving committee and board member of the Melbourne Cricket Club



David Parker AM

David Parker was appointed to the KHA board in April 2010, having previously chaired KHA's National Consumer Council. At present he is a deputy secretary in the Commonwealth Government's Department of Agriculture and Water Resources, with particular responsibility for water, the Australian Bureau of Agricultural and Resource Economics and Sciences (the department's economic and scientific research arm) and exports, trade and market access. Previously he was a deputy secretary in the Department of Environment and the Commonwealth Treasury. Whilst at the Treasury, from 1984 until February 2011, he spent some time working with the OECD in Paris. David has qualifications in economics and law and was made a Member of the Order of Australia in January 2012.



Prof. Carol Pollock

Professor Carol Pollock was appointed to the KHA board in December 2014. She has an international reputation for her work and publications relating to the aetiology and treatment of kidney disease. An inaugural fellow of the Australian Academy of Health and Medical Sciences, she 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 (which includes research into kidney disease). Among her many leadership roles, Carol was Scientific Chairman of the 2013 World Congress of Nephrology, and she chairs the ANZ Society of Nephrology Research Advisory Committee and the International Society of Nephrology Meetings Committee, which is responsible for research and educational meetings and policy forums around the world. At present she is chair of the New South Wales Bureau of Health Information and the New South Wales Cardiovascular Research Network.

1 in 3 Australians
is at increased risk of kidney disease



90%

of kidney function can be lost
without experiencing any symptoms



Kidney disease currently affects an
estimated 1.7 million Australians

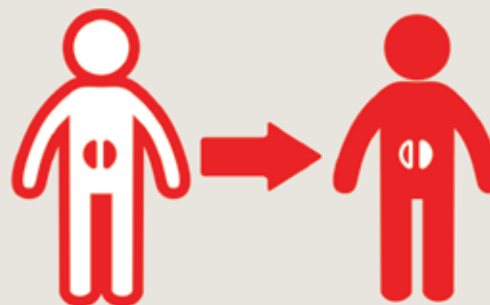


The average waiting time for
a transplant is about 3 years,
but waits of up to 7 years are
not uncommon

Every day, 60 Australians die
with kidney-related disease



12,461
Australians are on dialysis



955 Australians are waiting
for a kidney transplant

Kidney disease contributes
to approximately



of all hospitalisations in Australia

Most dialysis patients need
treatment at least 3 days a week
for 5 hours a session to stay healthy



Diabetes and high blood pressure
are two of the most common
causes of kidney disease



What can you do?
Your kidneys
look after you...
It's time to look
after them!



Maintain a healthy
body weight



Manage your
salt intake



Make water
your first choice



Monitor your
kidney health

About Kidney Health Australia



Kidney Health Australia was established in 1968 as the Australian Kidney Foundation. At first it consisted of an affiliation of state and territory bodies: it is now a cohesive national body—a not-for-profit organisation dedicated to improving health outcomes and quality of life for people living with kidney disease, their families and carers. Its funding comes primarily from the public, largely in the form of donations and bequests.

The term 'kidney disease' refers to damage to or disease of a kidney. The condition can lead to chronic kidney disease and ultimately kidney failure (also known as end-stage kidney disease). Among the causes of chronic kidney disease are high blood pressure, diabetes, obesity, tobacco smoking, history of heart disease or stroke, family history of kidney failure, history of an acute kidney injury, advanced age, and Aboriginal and Torres Strait Islander heritage.

The symptoms of the disease—which is often referred to as the 'silent disease' because there might be no warning signs—can be very general and include changes in the pattern and nature of urination, high blood pressure, muscle cramps, pins and needles in the fingers and toes, and headaches. It is important to remember that this disease is not just a disease of adults: it can affect people of any age.

One in three Australians is at risk of developing kidney disease, and it is estimated that 1.7 million adult Australians have biomedical markers of reduced kidney function or kidney damage. In addition, each year about 3000 people in Australia are diagnosed with kidney cancer, which accounts for about 2.5 per cent of all cancers in this country. Compared with other common types of cancer, however, fewer resources are devoted to kidney cancer, and sufferers can feel very isolated and anxious.

Kidney Health Australia works to alleviate this situation on many fronts - for example, funding research, providing services such as the Big Red Kidney Bus and the Kidney Kids Camp, producing educational material (for people living with kidney disease and their carers, GPs, and other health professionals), operating the Kidney Health Information Service, publishing a newsletter, *Kidney Community*, and reaching out by means of our website, on Twitter and on Facebook.





1

Our kidney community



Our kidney community

One in every three Australians is at increased risk of developing chronic kidney disease, and among Australians aged 18 years or more approximately one person in 10 has indicators of the disease. Less than 10 per cent of Australians with chronic kidney disease are aware they have the condition: that amounts to 1.5 million Australians.

Rates of chronic kidney disease among Indigenous Australians—especially those in remote areas—are much higher than those among non-Indigenous Australians, in particular because of higher rates of diabetes, high blood pressure, tobacco smoking and obesity in Indigenous communities. For example, in 2012–13 one in five Indigenous Australians aged 18 or more had indications of the disease and nine out of 10 people in this group were unaware of the disease's presence. Aboriginal and Torres Strait Islander people are almost four times more likely to die with chronic kidney disease as a cause of death compared with non-Indigenous Australians.

Our kidney community, however, consists not only of people experiencing kidney disease. It also embraces a wide circle of individuals and organisations—the families, friends and carers of people experiencing the disease; health professionals; volunteers and others in the caring community; health-promotion organisations; and many others.

Over the years, Kidney Health Australia has developed innovative community programs designed to develop and nurture strong relationships with young people and adults living with kidney disease and with their families and carers. Through our community leaders in each state and territory, we have been able to extend our reach in communities, especially in rural and remote areas. We provide tangible support and up-to-date and relevant information to people seeking help.



Peer support networks



One of Kidney Health Australia's many strengths lies in the peer support we offer through our kidney communities, which consist of groups of people experiencing kidney disease plus their families and carers. Facilitated by KHA but locally autonomous, these groups support people at any stage of kidney disease—people who are on dialysis, people who have had or are waiting for a kidney transplant, and people who have health conditions that can cause an impairment of kidney function.

The primary benefit of these groups is the opportunity they provide to meet other people who have experience of kidney disease. They represent a place where people can lean on and learn from each other, share information and mutual support, and realise that no one needs to deal with kidney disease alone. The newly diagnosed or those starting dialysis will learn from their peers about how to manage their daily needs, how to provide suitable care, and how to live more easily with kidney disease. The peer-supported experience extends to carers and family members, especially children. Community provides a sense of belonging in an environment that is safe and non-judgemental.

Kidney Health Australia connects with people experiencing the disease, their families and carers through these groups, offering links to our own organisation and to other community services.

Indigenous Australians

Our advocacy and partnership at a national level continues to be an important key activity in securing recognition about the impact of kidney disease on Aboriginal and Torres Strait Islanders. As a member of the National Close the Gap campaign, we seek to improve the health and life expectancy of Aboriginal and Torres Strait Islander people to that of the non-Indigenous population within a generation—to close the gap by 2030. The 2016 Prime Minister's Close the Gap report recognises the impact of chronic disease (including kidney disease) on the life expectancy target.

In 2016 Kidney Health Australia introduced a new primary care education module—Understanding Chronic Kidney Disease for Aboriginal and Torres Strait Islander Health Workers—funded by Perpetual IMPACT Philanthropy. Accompanying this training module are a resource package and a range of fact sheets covering the following topics:

- what our kidneys do
- what chronic kidney disease is
- kidney disease among Aboriginal and Torres Strait Islander peoples
- who needs a kidney health check
- how to keep healthy.





The National Consumer Council

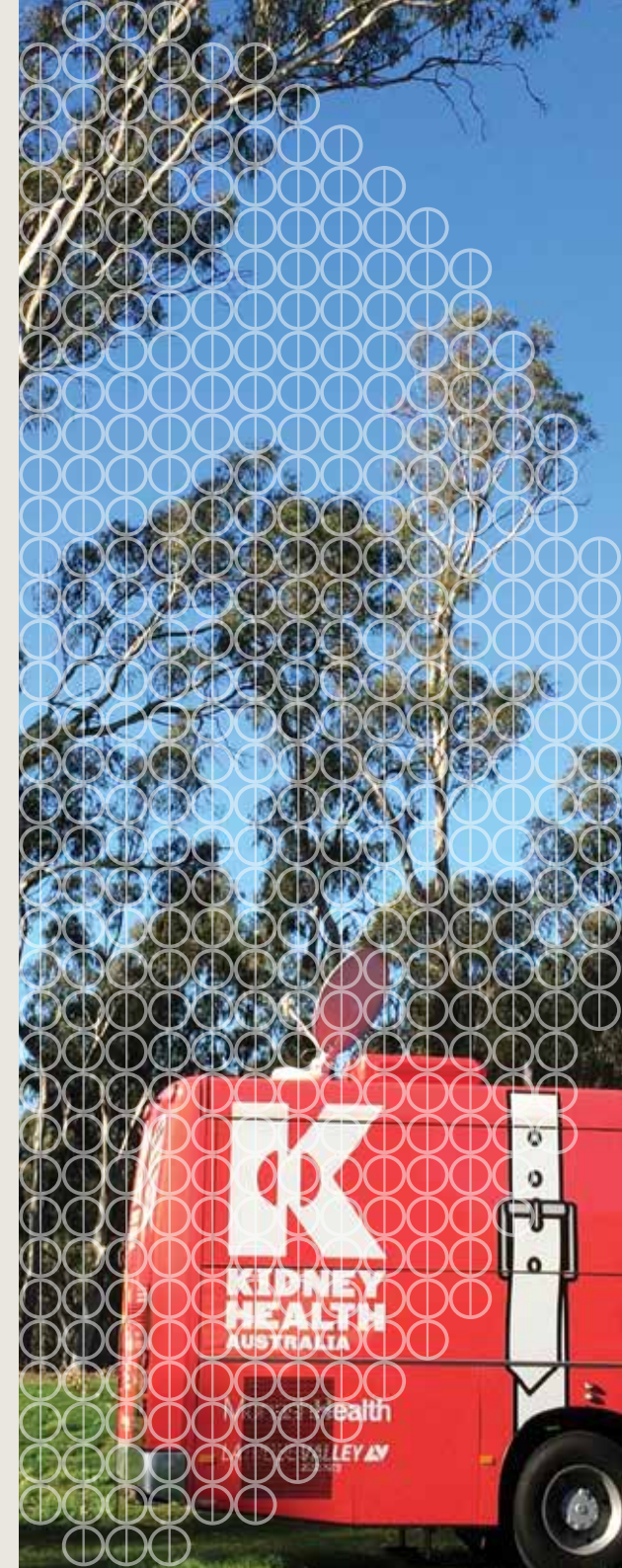
The National Consumer Council works at the national level to have a beneficial impact on the lives of people affected by kidney disease. It offers a formal pathway for people to gain attention in connection with the difficulties and opportunities they experience, and it is a mechanism for them to provide feedback to Kidney Health Australia on a wide range of topics. State and territory consumer committees operate at the local level to convey information about state and territory matters to the Consumer Council.

The purpose of these committees and the council is to help people living with kidney disease work collaboratively; they play an important role in bringing to light and dealing with challenges facing Australians living with their kidney condition.



2

Programs



The **Big Red** Kidney Bus



"The Big Red Kidney Bus is one of the best things I've ever seen. It's really amazing. I didn't expect it to be an actual bus! The bus showed me I could get away and feel free"

Alex Schlabowsky, 20, Bendigo



Delivery of one of our most innovative programs to date—the Big Red Kidney Bus—would not have been possible without the commitment of the medical and nursing team at Monash Health, led by Director of Nephrology, Professor Peter Kerr, along with Fresenius Medical Care, LaTrobe Valley Buslines, Ventura Buses and the Bus Industry Association Victoria. These individuals and organisations have generously contributed to the success of this world-first program, which offers a mobile dialysis service, allowing people to take a holiday whilst still receiving dialysis treatment.

To date, the buses have been operating in Victoria and New South Wales only, but pledges from clubs such as Lions and interest from the bus industry give us confidence that a further bus will be on the road, in New South Wales in 2017. Additionally, funds are being raised for buses in three more states by 2020.

In 2015 the Australian Government recognised the Big Red Kidney Bus holiday dialysis program through the National Disability Award for Excellence in Community Accessibility, and our partner Monash Health received the Gold Award for Innovative Models of Care at the Victorian Government's Public Healthcare Awards.

Kidney Health Australia's model has been to take the buses to holiday destinations selected by patients, allowing them to access treatment away from their home or local renal units. Excess dialysis capacity is also available in some circumstances for surge capability or emergency situations.



"I love the convenience and the opportunity to go away that the Big Red Kidney Bus gave us. We could have a break from home, and get away from the cold weather. My wife could relax and read books in the afternoon while I was at dialysis. We were also able to holiday with our friends"

Herwig Maxa, retiree, Melbourne

Kidney transplant houses

Kidney Health Australia operates a housing program in metropolitan centres that offers transplant patients from rural and regional areas comfortable, safe accommodation where they can prepare for or recover from transplant surgery.

The accommodation is also purpose-built to facilitate dialysis. Providing affordable accommodation is just another way that Kidney Health Australia assists in relieving the impact of kidney disease on patients and their carers.

Housing is provided in Brunswick, Melbourne, thanks to a generous donation from the Emorgo Foundation. The fully-equipped apartment has two bedrooms and is equipped with dialysis plumbing.

There are a further two houses in the Perth suburb of Morley named Haywood House and Hutchison House in recognition of two senior kidney specialists. A grant provided by Lotterywest funded the fit-out of the houses, which are available to rural families undergoing transplant therapy.



Kidney Kids Camp

For nearly 20 years, Kidney Health Australia has operated camps for children living with kidney disease. Our national Kidney Kids Camp was held in Queensland, at Runaway Bay Sports Super Centre, from 14 to 17 April 2016. The camp provides opportunities for children to holiday in conditions appropriate to their medical condition, continue the children's informal support networks of young peers, and provide respite to carers and parents for the period.

At the 2016 camp 72 children participated in the program. They ranged in age from seven to 17 years. They were supported by 100 volunteer carers, predominantly volunteer nursing students, 15 health professionals (including a nephrologist) and six Kidney Health Australia staff. Dialysis was provided on site or at Lady Cilento Children's Hospital in Brisbane.

Several hospitals offered the assistance of health professionals, and the camp would not have been possible without the help of staff from Adelaide's Women's and Children's Hospital, Melbourne's Royal Children's Hospital, Monash Children's Hospital, and Brisbane's Lady Cilento Children's Hospital. Education and nursing students from Southern Cross University and Queensland University of Technology comprised the basis of our volunteer force.

In response to feedback from older Kidney Kids and nursing staff, the 2016 program reintroduced the 'Young Hub' self-medication unit, which aims to encourage Kidney Kids over the age of 15 to become independent with their medication while in a supervised environment. Twenty-five Kidney Kids took advantage of the unit in 2016.

All activities and entertainment were aligned with a 'Superhero' theme, chosen to give an 'adventure' feel to the camp. The program included activities designed to build participants' self-confidence and provide creative opportunities for all campers. An excursion to Movie World offered participants a fun day out, but it was the in-camp activities that will be remembered most fondly. The 'Carnivale' street party, circus training, rock climbing, the camp concert and group chants gave kids a chance to break out of their shell.

The generous support of participants in and supporters of the 2016 Kidney Kar Rally allowed Kidney Health Australia to offer this fantastic experience at no cost to the families involved.





Young adults transition program



The rate of kidney transplant failure in young adults aged 18 to 25 years is the highest of any age group in Australia. Up to one third of transplanted kidneys fail to graft successfully. There are many reasons for this including the daunting nature of adult kidney care programs compared with those available in paediatric care and the sense of isolation teenagers entering adult programs can experience, with consequent reduced levels of participation.

Nephrologists at Royal Hobart Hospital, Royal Adelaide Hospital and Mater Misericordia Hospital in Brisbane have introduced a model of care, whereby young adults are brought together in dedicated clinics, in a group environment and outside the hospital, to mirror a 'youth club' and promote peer interaction and support. In 2016 Kidney Health Australia began providing a youth worker to act as a bridge between the healthcare team and patients, as well as to organise social activities, encourage life skills training and provide one-on-one support. Since the program has been operating no participating young adult has experienced transplant kidney loss. We are proud of this.

Henry Giblett adult holiday program

Many people receiving dialysis are dependent on an age or disability pension and are unable to participate in community events as a result of financial hardship. Kidney Health Australia helps redress this situation by providing holidays for those who would otherwise be unable to have a break away from home. Families with children also benefit from the opportunity to holiday and spend time with other families, and the program offers carers respite from the daily routines of dialysis and kidney transplantation-related regimes.

Under the program, free accommodation is provided at the Sebel Apartments in Busselton, Western Australia, two hours south of Perth. The area is ideal for adults and children, offering access to the Margaret River region, with its wineries, swimming, surfing and diving, tennis and other leisure activities. A kids club is also available, and Kidney Health Australia families receive meal subsidies and activity vouchers during their time away.

Kidney Health Australia and Fresenius Medical Care provide four dialysis bays, which are attended by a team of renal nurses, and Kidney Health Australia staff and volunteers assist with children's medical care. Our volunteers and staff also assist with transport and host social events, helping parents and carers enjoy their break.

The late Henry Giblett was a dialysis patient who allowed others to receive their dialysis treatment at his holiday home.





3

Services



Advocacy

Kidney Health Australia continued its advocacy activities during 2016; among other things, during the federal election campaign we sent a submission—‘Tackling Kidney Disease: a national action plan to reduce Australia’s kidney disease burden’—to all the major political parties, the then current and shadow health ministers, and other potentially influential candidates. The submission called for the introduction of specific policy measures designed to improve the lives of people with kidney disease and prevent progression to end-stage kidney disease.

The result of this lobbying was a commitment by the Australian Labor Party to establish a national taskforce, if elected, with \$295 000 set aside for this purpose, and a \$10 million commitment by the Australian Greens to developing a national taskforce and a range of CKD activities specifically for Indigenous Australians.

In support of its advocacy efforts KHA has also developed a four-point national action plan that, like KHA’s election submission, focuses on improving health outcomes and removing barriers to receipt of care. The plan covers four primary areas:

- It outlines policy changes needed to reduce the incidence of and delay the onset of end-stage kidney disease through more effective early detection and a quality practice incentive payment and an MBS item to enable the integrated health check.
- It supports a continued system for living organ donation, moving the Supported Leave for Living Organ Donors Program out of the biannual budget trial phase and making it a permanent initiative. Along with this, it calls for a funded national approach to increase rates of living donation, led by the Organ and Tissue Authority.
- It emphasises the need for a national taskforce to advise on how we can overcome barriers to tackling kidney disease in Aboriginal and Torres Strait Islander communities.
- It calls for a national strategy for kidney disease, with, among other things, a national approach to dialysis and better support for home dialysis.

The action plan is now being promoted to politicians, researchers, government officials and philanthropists. Other policy and advocacy initiatives will be released in 2017.



Kidney Health Information Service



Established by Kidney Health Australia in 1998, the Kidney Health Information Service is a free national phone-support service for people living with or affected by kidney and urinary disease. It offers information, support, referral and advice to patients, their families and health professionals, and callers are directed to the service that will best meet their needs.

The service responded to 2132 inquiries in 2016, and 3200 fact sheets, booklets and publications were distributed in response to these inquiries.

The following groups of people made contact with the service:

- patients—38 per cent
- carers, family members and friends—31 per cent
- health professionals—11 per cent
- others (students, public health employees, researchers, etc.)—15 per cent.

The inquiries most commonly covered the following subjects: dialysis (15 per cent); chronic kidney disease (12 per cent); travel, holidays and accommodation (8 per cent); organ donation (7 per cent); and diet and nutrition (7 per cent).

Kidney Community newsletter

Kidney Community is a free quarterly newsletter that has been very popular with the kidney community since it was established in 2011. It offers up-to-date information about kidney disease and the programs and services available and discusses other subjects of importance to the kidney community. Each issue features articles on the latest medical research and resources, patient stories and kidney-friendly recipes, as well as updates on Kidney Health Australia's advocacy efforts, programs and services, activities and key events.

There are 14 860 email subscribers and 1376 postal subscribers.



Kidney Health Australia website

kidney.org.au is a comprehensive resource centre, offering expert information, tools, and useful contacts. Visitors to the site can learn about their kidneys, prevention and detection of kidney disease, and much more. This is supported by online facilities, such as our Dialysis Unit Guide (DUG) tool and an eGFR calculator.

In addition, kidney.org.au also serves as an online support network—for example, through our Your Kidney Forum. This important aspect of the site allows members of our kidney community to connect at any time of the day or night, which helps to reduce the feelings of isolation many kidney disease patients experience.

kidney.org.au also encourages members of the kidney community to become involved in awareness-raising activities and volunteering programs. The site also promotes all of KHA's initiatives, advocacy work, support groups, and programs and services. The e-commerce element of the site supports revenue-raising initiatives by enabling online donations, K Lottery ticket purchases and an online shop.

Fully supporting user privacy, kidney.org.au complies with the HONcode standard for trustworthy health information and is an approved information partner of Health Direct Australia. KHA also partners with—and promotes—useful health and support organisations by cross-linking from the site.

In 2016, kidney.org.au received more than a million page views and was visited by more than 464 068 unique users.





4

Research



Grants and scholarships

In 2016 Kidney Health Australia awarded grants and scholarships to the value of \$206 000 for kidney-related research projects in university departments, medical research institutes and hospitals throughout Australia.

- \$62 000 was invested in two continuing PhD scholars conducting research into the role of immune cells in the kidney (Dr Peggy Teh) and problems with protein folding and trafficking as novel mediators of kidney disease (Mr Aowen Zhuang).
- \$9000 was invested in continuing grants for nurses pursuing master's degrees: Mrs Jo-Anne Moodie, Master of Nursing – nurse practitioner (University of Melbourne); Mr Grant Ramke, Master of Nursing – Clinical Education (James Cook University); Ms Laura Austin, Master of Nursing – Nursing Education (Charles Sturt University).

KHA also granted \$125 000 to the ANZDATA Registry and the Australasian Kidney Trials Network. The registry has contributed greatly to knowledge, planning and best practice in clinical care over many years; in 2016 it was awarded \$75 000 to go towards its general operating costs. The network, which designs, conducts and supports high-quality clinical trials aimed at improving life for people with kidney disease, was awarded a \$50 000 research grant.

Awards for Excellence

Each year Kidney Health Australia offers a \$5000 prize for the best clinical nephrology presentation at the Australia and New Zealand Society of Nephrology annual scientific meeting. This award is judged on abstract and presentation, and all presenting members of the ANZSN are eligible. The 2016 winner of the award was Ms Andrea Viecelli, from the University of Brisbane.

Additionally, KHA sponsors two annual awards, each to the value of \$1000, for the best clinical and laboratory research presentations at the Transplantation Society of Australia and New Zealand scientific meeting. These awards are also judged on abstract and presentation. The 2016 winner of the award for best clinical research presentation was Dr Wai Lim, from Sir Charles Gairdner Hospital; the 2016 winner of the award for best laboratory research presentation was Ms Evelyn Salvaris, from St Vincent's Hospital in Melbourne.

Priscilla Kincaid-Smith Kidney Research Foundation

Priscilla Kincaid-Smith AC CBE was a pioneer not only in Australian nephrology, but internationally. A true clinician-scientist and medical leader, she was an accomplished physician-researcher, a pathologist and nephrologist. One of her signal achievements was to demonstrate in the 1960s the links between the taking of headache formulations containing phenacetin (widely sold in Australia at the time as Bex and Vincent's APC) with the development of kidney disease and kidney cancer. She also worked on the links between high blood pressure and renal malfunction. Among other things, at various times in her career she was president of the Royal Australasian College of Physicians, the World Medical Association and the International Society of Nephrology.

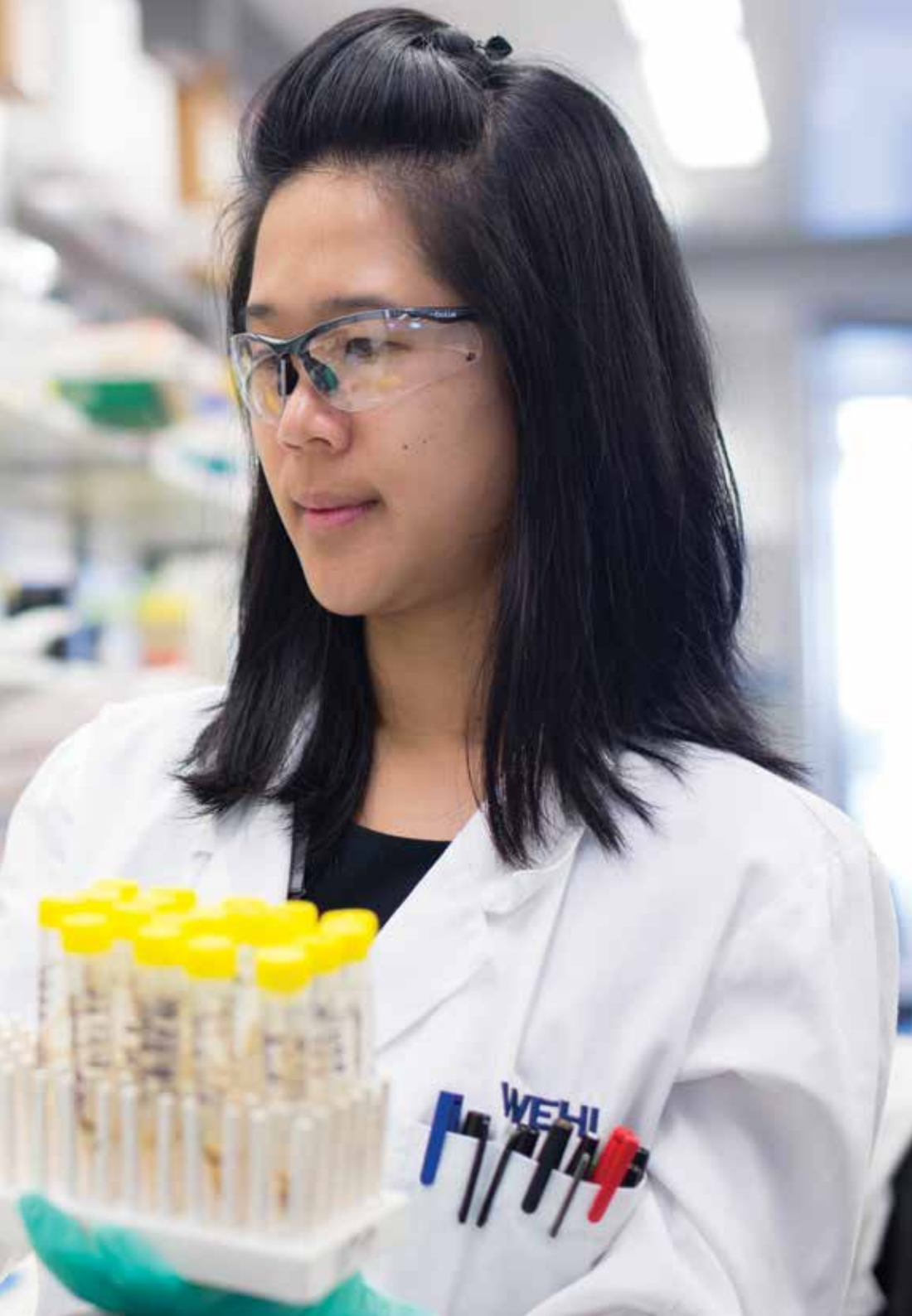
Kidney Health Australia established the Priscilla Kincaid-Smith Kidney Research Foundation with the broad mandate of promoting kidney research designed to improve and save the lives of Australians with kidney disease.

In 2016, the foundation assisted the following recipients:

- Laura Austin
- Prof. Melissa Little
- Jo-Anne Moodie
- Grant Ramke
- Dr Peggy Teh
- Aowen Zhuang.

In 2015–16 the foundation took part in a Delphi priority-setting survey to determine the research questions that are of crucial importance to Australians affected by end-stage kidney disease, clinicians and researchers. The survey results will be used to inform the development of the foundation's research agenda.





KHA-CARI Guidelines

The Kidney Health Australia – Caring for Australasians with Renal Impairment Guidelines are the outcome of an evidence-based project begun in 1999. The project is part-funded by KHA and managed by the CARI Guidelines Steering Committee.

The aim of the guidelines is to improve outcomes and the quality of care for paediatric and adult patients by helping physicians and other healthcare workers adhere to evidence-based clinical practice guidelines. Although developed for use in Australia and New Zealand, the guidelines are used more widely in the region; they are a valuable educational resource and offer a means of improving the quality, consistency and cost-effectiveness of renal health care.

Image courtesy of the Walter and Eliza Hall Institute of Medical Research.

Becky Johns Kidney Discovery Fund

The Becky Johns Kidney Discovery Fund, established under the Priscilla Kincaid-Smith Kidney Research Foundation, is named in honour of a Kidney Kid who later became a KHA volunteer and then a staff member. Under the fund, work is being done in the hope of discovering non-cancer inducing anti-rejection drugs for kidney transplant patients.

Born with infantile polycystic kidney disease, Becky died in November 2015, nine weeks after receiving a diagnosis of non-Hodgkin lymphoma and two days after her 23rd birthday. She had received two kidney transplants, one from her father and one from her mother, and it was the anti-rejection drugs that triggered her lymphoma.



Becky Johns pictured second from left.



WE
PLEDGE
TO HELP

LIVE
KIDNEY
DONORS
WHO

GIVE THE
GIFT OF
LIFE!



5

Education



Patients

To ensure optimum care, continuing communication between a person with chronic kidney disease and their health care provider is essential. Self-care is becoming increasingly common, and there is an expectation that patients will be able to comply with the advice provided in education materials. Producing education materials for patients has always been one of Kidney Health Australia's most important roles.

To date, we have produced over 50 fact sheets covering the diagnosis and impacts of kidney disease, co-morbidity, medications, kidney cancer, treatment options, nutrition, and kidney donation and transplantation. Additionally, we have collaborated with the Royal North Shore Hospital in Sydney to provide a comprehensive suite of handbooks for patients; these cover topics such as living with kidney disease, kidney failure, kidney cancer, supportive care, dialysis options, and nutrition.

Some of these publications have also been translated into other languages such as Arabic, Chinese, Vietnamese, Greek and Italian.



Health professionals



Kidney Health Australia produces a number of resources designed to help health professionals detect and manage kidney disease:

- Face-to-face and online world-class education modules that are designed to improve the knowledge, detection and management of kidney disease in general practice. Over 4000 hours of health-professional education was provided in 2016.
- ***The Chronic Disease Management in General Practice handbook***. Now in its third edition, this handbook provides a synthesis of evolving evidence showing the importance of early management of kidney disease. The book is designed to help health professionals identify people at risk of developing kidney disease and manage those who have chronic kidney disease. Over 2600 copies of this book were distributed in 2016.
- ***CKD Go!*** This is an app designed to help health professionals recognise, understand and manage chronic kidney disease. A user can view a personalised action plan based on the eGFR and the albumin–creatinine ratio. There were over 1200 downloads of this app in 2016.





School children

In 2016 Kidney Health Australia reached nearly 2000 students, teachers and parents through our Big Red Kidney Bus Education in Schools Project. Our education team visited 14 Primary and High Schools and two Universities. Locations included Traralgon, Sale, Albert Park, Bundulaguah, Fitzroy, Mildura, Echuca, Rochester, Halls Gap, Stawell and Brighton.

During each session students learnt about the importance of kidneys and how to keep their kidneys healthy. Students explored how the kidneys filter and clean the blood, the colour of healthy urine and the difference between natural and unnatural drinks such as orange juice and lemonade. Students discovered that there are 16 teaspoons of sugar in one 600ml bottle of soft drink, and that drinking one bottle of soft drink a day for an entire year would total 23kg of sugar. The students were also shown how dialysis works and how important programs like the Big Red Kidney Bus are to patients who require dialysis three times a week, five hours a day.

Kidney Health Australia received positive feedback from students and teachers. Eighty-two percent of grade 5–6 students reported that the sessions made them think about changing what they eat and drink. Fifty percent of students would like to consume more natural foods and make some changes to their school snacks. Eighty-five per cent of teachers reported that education made them think about changing the way they eat and drink and 53 per cent intended to drink more water following our sessions.

6

In the
spotlight



Kidney Health Week

Kidney Health Week is our primary awareness-raising activity for the year. Between 22 and 29 March 2016, the theme of the campaign was 'I Kidney Check', and encouraged everyday Australians to take control of their kidney health and get their kidneys checked.

Our online 'I Kidney Check' gallery featured stories of people who have been affected by kidney disease, either directly as a patient themselves or indirectly as a family member, carer, or friend of a patient. Several of Kidney Health Australia's Ambassadors also shared their stories in the gallery.

Yet again, our kidney community did us proud all around the country holding events, manning kidney health information stalls, and drumming up publicity in their local areas to help spread the word and raise vital awareness for the kidney cause. We thank each and every member of our community for their support.

Throughout the week messages of awareness and prevention, told via stories of real people's experiences living with kidney disease, were heard right across Australia as media got behind the campaign and helped to amplify it. Of all the media coverage, two powerful interviews with former Kidney Kid turned Kidney Health Australia staff member, Grant Monks, were certainly amongst the highlights. Grant shared his story about life with kidney disease and living on dialysis with radio legend Alan Jones, as well as with Channel Nine News veteran, Brett McLeod.

For the first time ever our 'State of the Nation' report utilised previously unpublished data from the Australian Health Survey 2011–13 to identify the top 20 Australian chronic kidney disease hot spots, based on the proportion of the adult population within each Medicare local catchment area with biomedical signs of CKD.

The official hashtag (#KHW16) reached 1.1 million users on Twitter and Instagram alone, thanks to the support of our ever-growing kidney community and the network of influential health organisations that helped spread the kidney health message.

Our own Kidney Health Week Facebook posts reached a record 631 000 people; thanks here are due in part to official ambassadors such as co-captain of the Greater Western Sydney Giants, Phil Davis, and inspirational KHA spokesperson Grant Monks, who is a staff member and also lives with kidney disease. Testament to the power of storytelling, Grant's video, in which he speaks of his experience living with kidney disease in order to help Australians understand the importance of having a kidney check, became the most popular social media post of the year, reaching more than 75 000 people.

In conjunction with Kidney Health Week, in 2016 Kidney Health Australia introduced a new awards program with the objective of acknowledging excellence in the detection and management of chronic kidney disease in primary care. A broad range of nominations were received in the categories of primary care individual, primary care clinic or group, and other primary care organisations. The awards were adjudicated through PEAK, an expert committee comprising prominent kidney specialists, health professionals and educators. The following individuals and organisations were awarded:

- overall winner and category winner, general practice—Aberfoyle Park Medical Centre, South Australia
- runner-up and certificate of excellence—Shoalhaven Family Medical Centres, New South Wales
- category winner, individual—Ms Sarsha Kalker, registered nurse, Victoria
- category winner, other—Bulgarr Ngaru Medical Aboriginal Corporation, New South Wales
- certificate of excellence—Dr Wayne Cooper, general practitioner, New South Wales.





Kidney Health Research Walk



Kidney Health Australia held its national Research Walk on 11 September 2016. More than 3000 enthusiastic supporters participated in walks across the country.

All around Australia, the kidney health community gathered in red attire and fancy dress in Australian parks, walking trails and coastlines, across Adelaide, Brisbane, Canberra, Launceston, Melbourne, Perth and Sydney. Supporters also hosted their own walks in Port Macquarie, Raymond Terrace, Hervey Bay, Rockhampton, Toowoomba, Townsville, Hobart, Coorow and Geraldton. Walkers and runners of all ages and abilities were accommodated.

Kidney Health Australia's Research Walk brings our community together, and raises awareness of the impact kidney disease is having on Australians. All proceeds help support our research programs and initiatives aimed at improving the lives of people affected by kidney disease.



Kidney Kar Rally

The first Kidney Kar Rally was held in 1989. As well as offering an exciting and memorable experience and being an important fundraiser for Kidney Health Australia, the purpose of this annual event is to raise awareness of kidney disease: at major stops on the trip KHA staff educate local communities about kidney disease and the importance of prevention, detection and support.

The 2016 rally covered the distance from Bathurst to Taree via Dubbo, a trip of more than 700 kilometres. Fifty-five rally teams participated over eight days. Over 200 participants took part in the event which raised money for our national Kids Camp.

A huge congratulations to the top three placing teams, Team O'Halloran in 1st place, Learning To Fly in 2nd place and Grimace Too in 3rd place. Whilst the rally made its way across NSW, our Support team also visited nearby schools and renal units, sharing kidney health information with the students and health professionals.



Patrons and ambassadors

We are extremely honoured and grateful to have the following patrons and ambassadors for Kidney Health Australia. With their assistance, we have been able to raise awareness about the importance of kidney health and how to potentially reduce the risk of kidney disease.

- Patron-in Chief—His Excellency the Honourable Sir Peter Cosgrove AK MC
- Patron—Lady Margaret Brabham
- Patron—Normie Rowe AM
- Ambassador—David Hussey
- Ambassador—Frankie J Holden AO
- Ambassador—Phil Davis
- Ambassador—Rochelle Pitt
- Ambassador—Sharna Burgess.



Social and digital media

Throughout 2016, engagement across all of KHA's social media channels increased by 15 per cent. We reached 2.8 million people through Facebook alone, a 53 per cent increase on 2015, and Instagram quickly became our second most popular channel, with a 481 per cent increase in engagements.

It is exciting to see the community interacting so enthusiastically—not only with us, but also with one another—and contributing to conversations about KHA's events and programs, and discussing the positive impact of KHA's support services, information and resources—especially relating to mental health.

In summary:

- Facebook fans grew to 12 548, an increase of 39 per cent on 2015
- Instagram followers grew to 1236, an increase of 255 per cent
- LinkedIn fans grew to 498, an increase of 44 per cent
- Twitter followers grew to 2441, an increase of 24 per cent.

"We reached 2.8 million people through our official Facebook Page"





7

Finances



Finances

Kidney Health Australia's result for 2016 (after grant allocations) was an operating loss of \$652 700 compared to an operating loss of \$758 559 for the previous period.

KHA reviewed its business strategy in 2016 and drawing on the external review of its business model undertaken in 2015 by PwC, focused on improving its traditional revenue base and developing sustainable new activities.

KHA's priority activities continued to be in the areas of education, advocacy, research and support. The Big Red Kidney Bus holiday dialysis program continued to provide a much-needed service for people on dialysis and their families; the expansion of the transplant housing program did the same for rural, regional and interstate transplant recipients.

At 31 December 2016, Kidney Health Australia had 62.01 FTE employees (31 December 2015: 77.73 FTE employees).

Our short-term business priorities centre on the delivery of support to Australians with kidney disease whilst ensuring a community focus on early detection and prevention through education, awareness, research and support with an Indigenous focus in all areas.

Our short-term strategic goals include:

- increased community/stakeholder engagement
- continued provision of educational content
- increased support to the kidney community
- commitment to research through the Priscilla Kincaid-Smith Kidney Research Foundation
- establishment of more revenue streams.

Kidney Health Australia's long-term strategy takes into account the challenges faced by the kidney sector for health policy recognition of kidney disease as well as the challenges and opportunities faced within the current economic operating environment.

Our long-term strategic goals include:

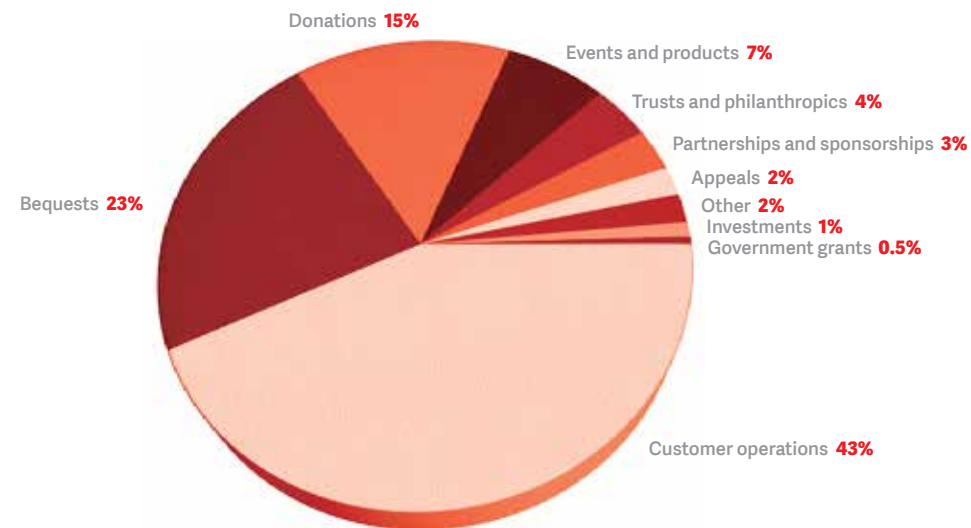
- increased awareness via engagement with the kidney community
- increased prevention, early detection and best-practice management of kidney disease
- improved access and equity to kidney treatment and support
- sustainable and relevant kidney research.

For more detailed information, you can view our complete financial statement at www.kidney.org.au

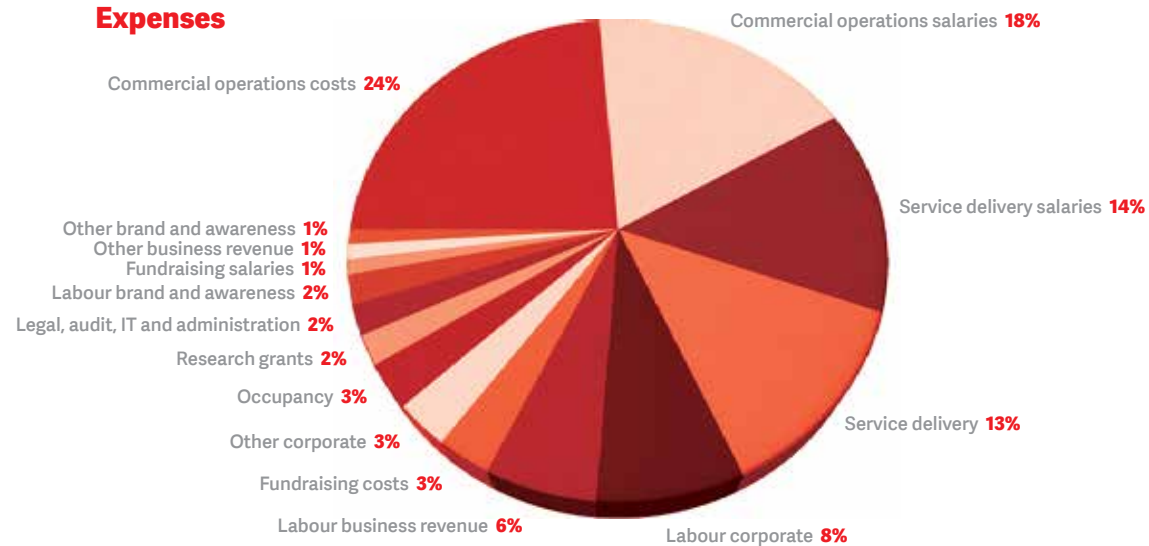
Financial position as at 31 December 2016

	2016	2015
	\$	\$
Assets		
Total current assets	1,544,512	1,083,114
Total non-current assets	4,509,204	5,770,496
Total assets	6,053,716	6,853,610
Liabilities		
Total current liabilities	1,924,480	2,264,871
Total non-current liabilities	355,426	351,848
Total liabilities	2,279,906	2,616,719
Net assets	3,773,810	4,236,892
Equity		
Total equity	3,773,810	4,236,892

Income



Expenses






LOVE

#Awesome

#Happy

KIDNEY HEALTH
RED KIDNEY



8

**The people
we'd like
to thank!**

Bequests realised in 2016

We acknowledge and remember the following generous donors whose bequests were realised in 2016.

Estate of Henry Creed
Estate of Peggy Eggar
Estate of William Evans
Estate of Janet Greenshields
Estate of Alan Hall
Estate of Judith Harper
Estate of Thelma Jeffrey
Estate of Jesse Jones
Estate of Marion Kingston
Estate of Marjorie Lawn
Estate of Iris May Lee
Estate of Eileen Maloney
Estate of Paula Maloney
Estate of Lynette McSevney
Estate of Teuntju Meischke
Estate of William Melehan
Estate of Jean Merchant
Estate of Sheila Perryman
Estate of Joyce Price
Estate of Margaret Reid
Estate of Silvia Richardson
Estate of Joyce Robinson
Estate of Helen Sattell
Estate of Elizabeth Schultz
Estate of Lesley Seres
Estate of Dorothy Simblett
Estate of Keith Stanford
Estate of Alan Weinand
Estate of Dorothea Whitfield

Major donations and fundraisers

We sincerely thank the following major donors and fundraisers for your generous support in 2016.

Nicholas Aitken
Jack Anastasakis
Rita Andre
George Andrews
Saundari Appu
Ray Aurisch
Gladys Barnes
Linda Bennett
June Bramich
Neville Broome
Chelsea Bury
Michael Cherry
Barbara Cimetta
Phillip Coleman
Dyke Dunning
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Felicity Greenrod
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Darren Quinn
Michael Ronai
Kenneth Russell

Dominic Sadsad
Quin Scalzo
Daniele Schieven
Peter Siminton
Kon Stamopoulos
Harry Tamvakeras
Bruce Verity
Pamela Wall
Linda Warszewski
Barney Williamson
Justin & Carolyn Wood

Community fundraisers

Kidney Health Australia thanks its community fundraisers who not only raise money, but who also raise awareness of the impact of kidney disease in their communities.

AON Charitable Foundation
Jeanine Bachelor
Central Coast Support Group
Rosa Chirumbolo
Philip Coleman
Dyke Dunning
Marks Family
Garnett House, Geelong Grammar School
Lucy Jackson & Geoff Bungey
Godfrey Hirst Australia
Jenny Hagiliassis
Katy Honig
Alf Hurley
Carmel Matsso
Ondrea Middleton
John & Joan Mitchell
Mandy Moore
Monaro Car Club NSW
Queensland Urology Nurses Society
Salisbury Philatelic Society Inc
Scalzo Food Industries
Kim Shaw
Thomas Singer
South 32
John & Peter Tassoulas
The Wynyard Chorale Inc.
Brian Thomas
Fay Winston



Operation Angel

Operation Angel Awards recognise members of our kidney community who are doing remarkable things for people living with chronic kidney disease. Operation Angel recipients can be patients, carers, health professionals, volunteers, or any person or group that has made a significant contribution to the kidney community in Australia.

In 2016 we acknowledged the outstanding contributions on nine Operation Angel Award recipients. Their passion and dedication to helping those living with kidney disease makes such a difference in their community, and we proudly welcome them to the ranks of Operation Angel recipients.

- Paul Basket (NSW)
- Marita Vecchio (NSW)
- Margaret Wayne (NSW)
- Clint Adams (TAS)
- Alison Bowkett (TAS)
- Myra Wrightman (TAS)
- Leonie Notte (WA)
- Maureen Bonra (WA)
- Tanya Chatfield (WA)



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.

- Australian Executor Trustees Limited
- Bell Charitable Fund
- Bofac Foundation
- Bowen Foundation Inc.
- The CMV Foundation
- Emorgo Foundation
- Fay Fuller Foundation
- Fred Pham Foundation
- James N. Kirby Foundation
- Joe White Bequest
- Lord Mayor's Charitable Foundation
- LotteryWest
- Newman's Own Foundation
- Pethard Tarax Charitable Trust
- Phillips Family Foundation
- Randall Foundation
- Rowe Family Foundation
- State Trustees Australia Foundation
- The Eirene Lucas Foundation
- The Harry F Carter Charitable Trust
- The Isabel & John Gilberston Charitable Trust
- The M.A.S.T. Foundation
- The Miller Foundation Ltd
- The Pethard Tax Charitable Trust
- The William Angliss (Vic) Charitable Trust
- The William Angliss (Qld) Charitable Trust
- The Stan Perron Charitable Trust



Primary Care Education volunteers

Our program simply would not exist without the nephrologists, GPs, renal nurses, Primary Care nurses and educators members of our Primary Care Education Advisory Committee for Kidney Health Australia (PEAK). Nephrologists and renal nurses also volunteer their time to present educational workshops to primary care health professionals, and volunteers also assist the KHA education team with administrative tasks. In 2016, volunteers donated an enormous 805 hours of their time to our primary care education program. This is equivalent to a value of \$135 800.

PEAK members in 2016:

Prof. David Johnson (Chair)
Dr Chris Bollen
Dr Katherine Fawcett
Kathryn Godwin
Barbara Harvie
A/Prof. Meg Jardine
A/Prof. Ivor Katz
Prof. Robyn Langham
Dr Amanda Mather
A/Prof. Craig Nelson
Dr Richard Phoon
A/Prof. Kevan Polkinghorne
Dr Angus Ritchie
Dr John Saunders
Wendy Shepherdley
Prof. Tim Usherwood
Dr Sheena Wilmot
Dr Jacqui Hughes (PEAK advisor)
Graz Hamilton (AIHW)
Breonny Robson (ex-officio)
Dr Marie Ludlow (ex-officio)
Claire Sheeky (ex-officio)

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
Astellas Australia
Bristol-Myers-Squibb
IPSEN
Novartis
Otsuka Australia
Roche
Sanofi
Pfizer

Kidney Health Australia is most grateful for the bequests, donations, community fundraisers, lottery ticket supporters and other assistance we receive. Without the generosity and support of our many benefactors, we would not be able to continue helping to ease the burden for people living with kidney disease.

Volunteer
with us.

Become involved in
community fundraising
and other events.

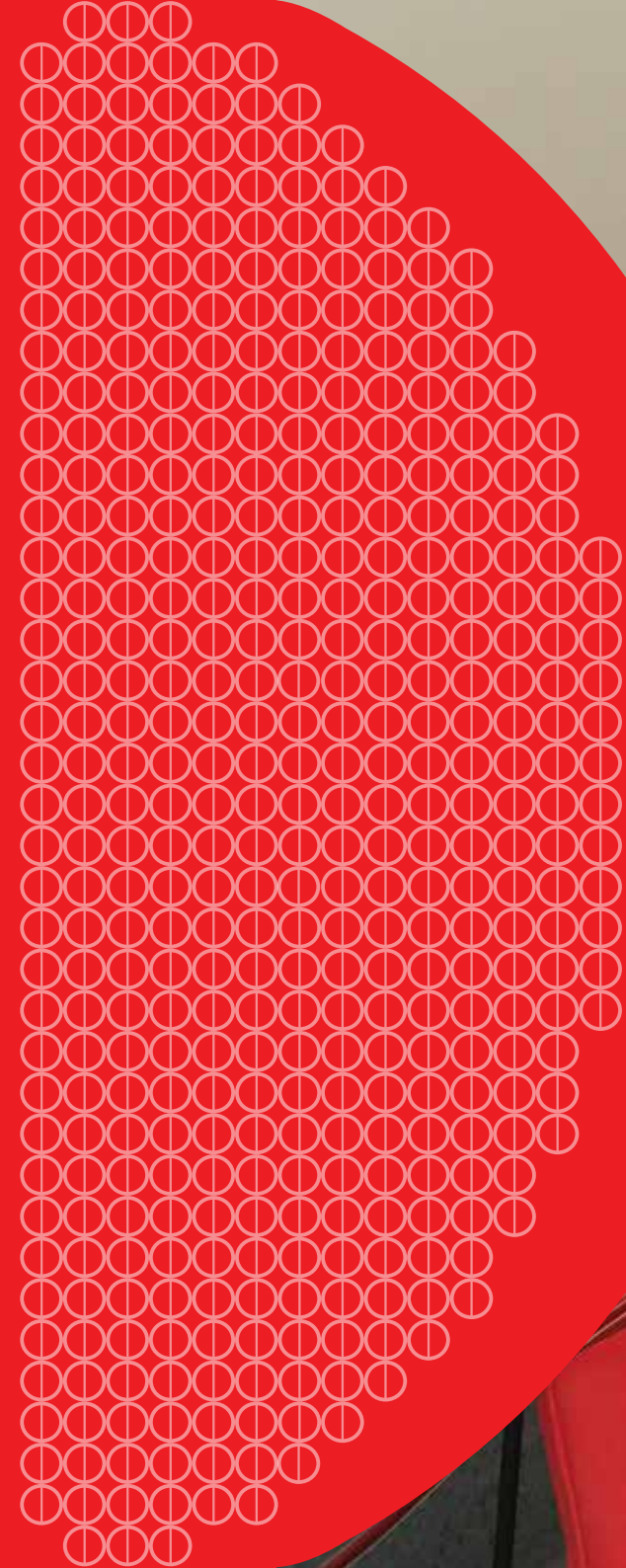
Please consider making
a **cash donation**.
Every dollar helps us to
deliver our vital programs
and services.
All donations of \$2 or more
are tax deductible.

How to help

Buy tickets in
our lotteries.
'Win big' and support
us in delivering our
programs and services.

Donate through
your employer's
workplace giving
program.

Talk to us about
making a gift
in your Will.







Connect with us:

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www.kidney.org.au



Prevent, Detect, Support.