

# TACKLING KIDNEY DISEASE

A national action plan to reduce Australia's  
kidney disease burden



*"Reducing the dialysis burden and premature death through  
smarter early detection, targeted primary care interventions,  
increased organ donation, education and carer support."*

[www.kidney.org.au](http://www.kidney.org.au)

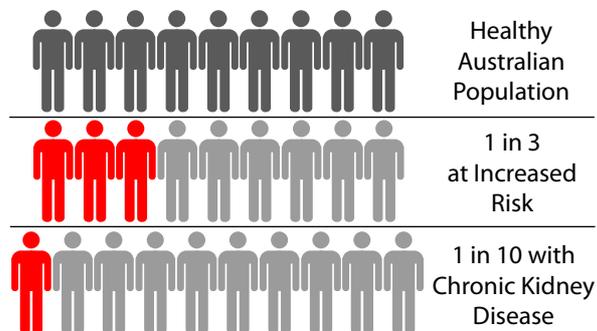
## The Rising Burden of Kidney Disease

Chronic Kidney Disease (CKD) is a major health problem and its incidence is growing.

Kidney Health Australia estimates that 1 in 3 Australians are at an increased risk of developing CKD<sup>1</sup>, with the risk being even higher in those most vulnerable in our community. Approximately 1.7 million Australians aged 18 years and over - a striking 1 in 10 - have at least one clinical sign of CKD. And the situation is much worse for 'at risk groups'.

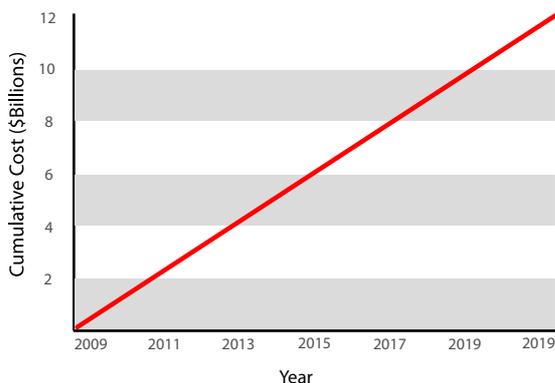
Kidney disease represents a significant and growing burden to the health system. It carries a considerable cost in health expenditure and forgone productivity. The Australian Institute of Health and Welfare estimates that the number of people on dialysis is expected to increase by 80 percent by 2020 - rising from 11 to 19 per 100,000 of the Australian population<sup>2</sup>.

### How much CKD in Australia?



**1 in 1400 on dialysis or living with a transplant.**

### Projected treatment costs for all new & existing kidney patients



Despite costing governments in Australia approximately \$1 billion per year<sup>3</sup>, kidney disease has received little attention. The cumulative cost of treating all current and new cases of end stage kidney disease from 2009 to 2020 is conservatively estimated to be between approximately \$11.3 billion and \$12.3 billion (in 2009 dollars), representing potentially more than 30,000 people on dialysis.

The most recent data from the Australian Bureau of Statistics (ABS) show that kidney failure is a significant cause of death. In 2011, diseases of the kidney and urinary tract were the 10th leading cause of deaths in Australia, with 3,386 deaths<sup>4</sup>.

**There has been a 45 percent increase in deaths from chronic kidney disease since 2000. More people die from diseases of the kidney and urinary tract each year than breast cancer, prostate cancer or even road deaths.**

<sup>1</sup> Chadban SJ, Briganti EM, Kerr PG et al. Prevalence of kidney damage in Australian adults: The AusDiab kidney study. J Am Soc Nephrol 2003 July;14(7 Suppl 2):S131-S138.

<sup>2</sup> AIHW 2011. Projections of the incidence of treated end-stage kidney disease in Australia, 2010-2020. Cat. no. PHE 150. Canberra:

<sup>3</sup> Cass A et al. The Economic Impact of End Stage Kidney Disease in Australia: projects to 2020. Published 2010.

Available at: <http://www.kidney.org.au/LinkClick.aspx?fileticket=vave4WFH73U%3d&tabid=635&mid=1837>

<sup>4</sup> Australian Bureau of Statistics. Causes of death, 2010. 2012.

## Action Plan for Positive Change

Kidney Health Australia is advocating for adoption of this action plan to address the growing burden of kidney disease. These initiatives seek to improve the health of those with kidney disease, while delivering improved efficiency and effectiveness to an already burdened health system. Each is grounded in persuasive evidence that action is needed, and where there are clear potential benefits for people living with kidney disease.



The priority initiatives identified in this proposal focus on improving health outcomes, removing barriers to care and **are aimed at making savings to the national health budget through a reduced need for dialysis.**

Firstly, it outlines practical, clear and achievable policy changes to reduce and delay the onset of end stage kidney disease through more **efficient, effective early detection.**

Secondly, this action plan outlines what we need to do in order to better **support our carers,** as they are crucial to the life of someone on home dialysis.

Thirdly, this action plan charts a course for **a better system for live organ donation** in this country, targeting what needs to be reformed at a governance, hospital and donor level.

Fourthly, this action plan highlights real, practical steps that can be taken to **tackle kidney disease in Indigenous Australians,** while reiterating the need to adopt the recommendations of past studies such as the Central Australian Renal Study.

Fifthly, it outlines a package of measures designed to **raise awareness, educate and support those in the community.**

Finally, it highlights the current lack of **research funding** in this disease, and provides a roadmap to the research areas in most urgent need of attention.

### Check List for Change

- 1** Efficient, effective early detection at the primary care level
- 2** Better support the carers of those living with kidney disease
- 3** Create a better system for live organ donation
- 4** Tackle kidney disease in Indigenous Australians through prevention, treatment, education and governance
- 5** Raise awareness, support and education surrounding this 'silent killer' at a community level
- 6** Address research funding for kidney disease through focussed priorities, including developing a renal services plan

**"This action plan presents a package of evidence-based and cost-effective interventions spanning improved early detection, carers, live organ donation, education and helping those most in need."**

## 1. More efficient, effective early detection

CKD is often regarded as a 'silent' killer, as up to 90 percent of kidney function can be lost before symptoms are evident. Data highlights that 10 percent of people attending general practice have CKD, but most do not know it<sup>5</sup>.

Similarly, every second patient that visits their general practitioner with type 2 diabetes will also have CKD<sup>6</sup>. CKD is a significant risk factor for vascular complications and for progression to kidney failure. Strikingly, among those with CKD, the risk of dying from cardiovascular events is up to 20 times greater than the risk of requiring dialysis or transplantation<sup>7</sup>.

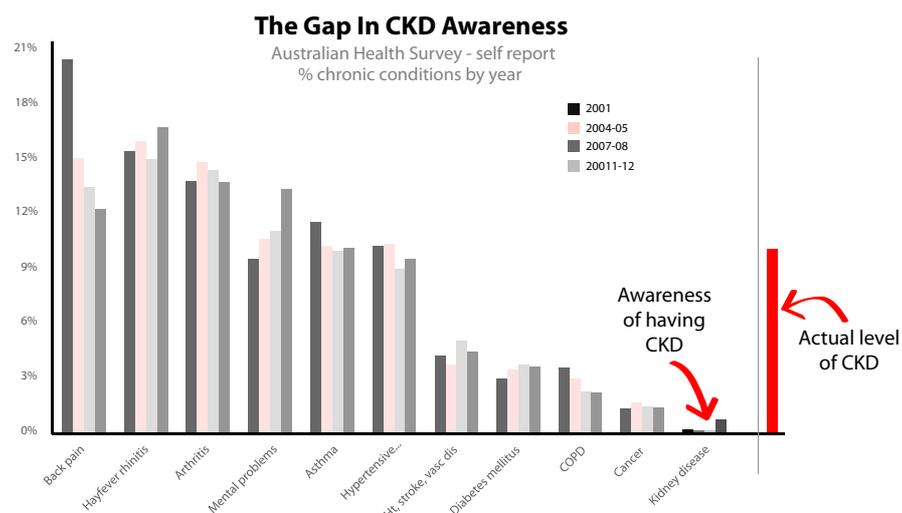
Despite these facts, if CKD is detected early and managed appropriately, the risk of cardiovascular events can be controlled, and the rate of deterioration in kidney function can be reduced by as much as 50 percent, and in some cases the deterioration may even be reversible<sup>8</sup>.

Early detection of CKD at the primary care level is therefore critical to stemming the tide. It is also the most logical location for such an intervention - 83 percent of Australians visit their general practitioner at least once a year<sup>9</sup>.

Over the past decade Kidney Health Australia has implemented the Kidney Check Australia Taskforce (KCAT). This one of a kind, evidence-based program seeks to educate primary health care professionals on best-practice approaches for the detection and management of CKD. To date, KCAT has utilised limited funds to educate over 15,000 health professionals in over 800 workshops, not to mention the additional numbers educated through our online learning modules.

In addition, Kidney Health Australia has developed the 'Chronic Kidney Disease Management in General Practice' handbook, a key to the management of chronic disease for General Practitioners. Now in its 2nd edition, this handbook has been provided free-of-charge to every general practitioner in the country, with an additional 5,000 copies ordered by health professionals every year.

However, the detection and management of CKD in general practice remains suboptimal<sup>10</sup>. Further work is needed to integrate early detection and management of CKD into routine clinical care.



<sup>5</sup> SAND abstract No. 163 from the BEACH program: Chronic kidney disease in general practice patients. Sydney: FMRC University of Sydney, 2011.

<sup>6</sup> Thomas MC, Weekes AJ. Type 2 diabetes from the GP's perspective. Kidney Health Australia, Melbourne, Vic; 2007.

<sup>7</sup> Keith DS, et al. Longitudinal follow-up and outcomes among a population with chronic kidney disease in a large managed care organization. Archives of Internal Medicine. 2004;164:659-663.

<sup>8</sup> Johnson DW. Evidence-based guide to slowing the progression of early renal insufficiency. Intern Med J 2004;34(1-2):50-7.

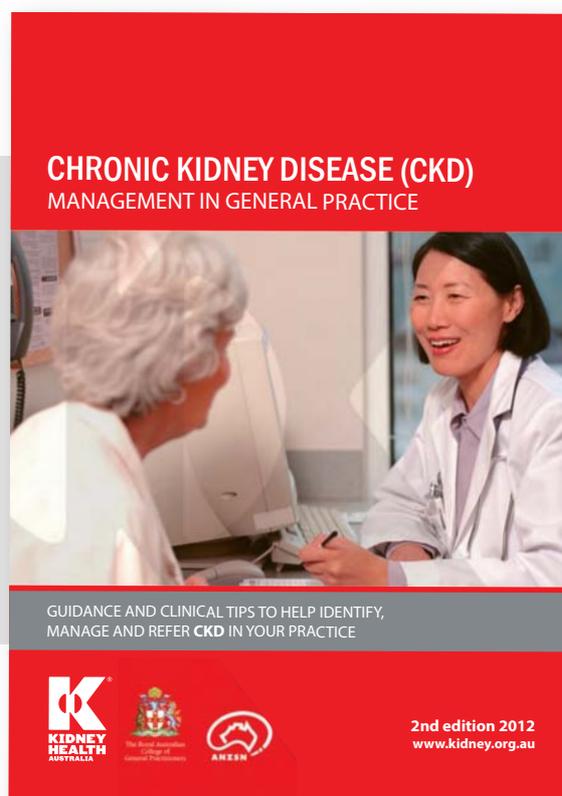
<sup>9</sup> BEACH Report, 2011-12, p.7

<sup>10</sup> Pilotto LSJ, et al. Electronic records suggest suboptimal management of chronic kidney disease in general practice. Aust J Rural Health 2012;20(4):195-9.

## What needs to be done?

- **Better Detection:** Introduce a comprehensive Integrated Health Check for kidney disease, heart disease, stroke and diabetes in primary care.
  - **Refer** those at risk to lifestyle modification programs and treatment, supported by an appropriate level Practice Incentive Payment (PiP).
  
- **Improved Education:** Expand the existing KCAT program to develop education resources for general practitioners and practice nurses, to address the following areas of need:
  - **Support** practice nurses and general practitioners to include measurements of kidney function into the Diabetes Annual Cycle of Care
  - **Increase confidence** of practice nurses and general practitioners to utilise the latest clinical tools and action plans
  - **Provide resources** to practice nurses to enhance their ability to detect and manage chronic diseases
  - **Engage** community pharmacists to recognise people at increased risk of developing CKD, undertake in pharmacy risk assessment (product being developed by Kidney Health Australia) and refer appropriately to primary care
  
- **Needs Assessment:** Establish the current knowledge of CKD best practice guidelines in general practice via a comprehensive study.
  - **Target** resources and education where it is most needed

Kidney Check Australia Taskforce (KCAT)  
CKD Management in  
General Practice Booklet



## 2. Supporting Carers

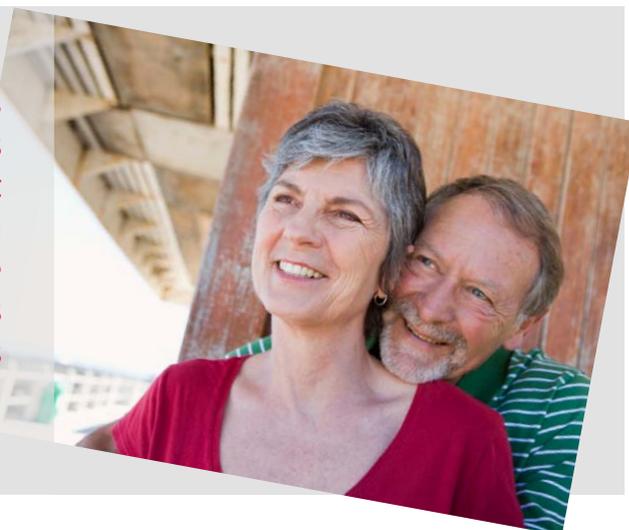
Living with kidney disease is an ongoing struggle. Dialysis, at a minimum, takes four to five hours at a time, three times a week. It requires either travelling to a satellite centre or hospital frequently, or undertaking dialysis at home.

For home dialysis, it often requires the support of a Carer, to set up, monitor and reset the dialysis machine. This caring role can stem from 15 hours a week to in excess of 35 hours a week to assist with machine set up and cleaning, inserting needles, preparing meals, managing blood pressure and troubleshooting any issues. Carers for home dialysis patients also require a significant investment of up to 6-8 weeks to participate in home dialysis training.

Mobility and independence is dramatically reduced while undergoing dialysis. Transport to and from medical appointments, plus attendance at appointments, is often an added responsibility, as is the need to often limit work and recreational activities in favour of fulfilling their role as Carer. Carers play a particularly pivotal role in supporting home dialysis patients, especially if the patient is a young child, has limited mobility, dexterity or movement or has failing memory.

Whilst the majority of Carers for dialysis patients believe their caring role is rewarding, caring is not always easy and comes at a cost. Carers have poorer health and well-being than non-Carers, and their responsibilities can adversely impact on family relationships, social networks, employment opportunities and finances.

Joan in Tamworth is the Carer for her husband (Ted) on dialysis. Joan doesn't drive and is always on hand to help Ted with his dialysis and ensure he has food, drink and comfort while he's dialysing. Ted is used to Joan doing this and has expectations she'll always be there to do this, so Joan feels guilty and turns down any invitations to socialise separately as she couldn't get to them anyway unless Ted opts to drive her.



## What needs to be done?

- **Financially support** the Carer who enables home dialysis through access to Carer's income. Despite the significant saving home dialysis provides Governments, many dialysis Carers are currently excluded from Carer's payments.
  - A separate category of payment should be introduced, and could be easily implemented.
- **Address inequity** in the level of access to and availability of psychosocial support and counselling for Carers of dialysis patients, particularly for those living in remote and regional areas.
- **Create** interactive, low cost networking and education initiatives
  - Web-based seminars that combine education sessions with opportunities for participant engagement and sharing (modelled on the current Kidney Club face-to-face meetings).
  - Opportunity to connect patients and Carers to exchange views, advice, information and support on topics such as self-management, nutrition and exercise, social support and well-being.
- **Provide respite** support to Carers to enable relief from caring responsibilities, and address cost and transportation challenges for the Carers. For those Carers who travel to in-centre dialysis, this may involve giving them access to Carer services in the centre.
- **Fund alternative** approaches in respite care, such as a nursing home, for certain categories of dialysis patients or increased in-home nursing options to support home dialysis.

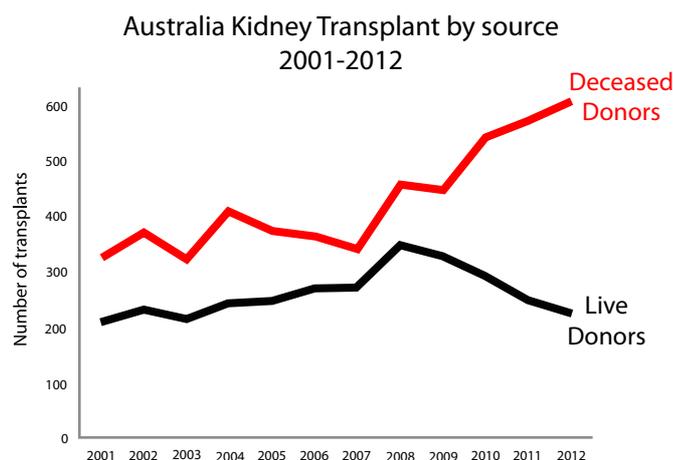


Mia in Mt Isa is the carer for her husband who is on peritoneal dialysis. She has to help him do his 'exchanges' as he has bad arthritis in his hands. Concerned that her mother had no respite from this daily regimen, her daughter bought Mia a ticket to a concert in Brisbane as a treat. Unfortunately as there were no other support people to take over the care of her father, her mother couldn't go. As a result Mia reached distress levels that should never have been experienced, and her husband felt guilty that he was such a burden to his wife.

### 3. A better system for live organ donation

The work program by the Australian Organ and Tissue Authority (DonateLife) over the last four years has seen a substantial and sustained increase in the number of deceased donors being made available for kidney transplantation. This change has however not been accompanied by an increase in the total number of kidney transplant operations, due to a 33 percent fall in the number of live kidney donors over the same time.

While live donor kidney transplantation has existed in Australia from the earliest days of transplantation, it peaked in 2008 when it accounted for 44 percent of the total transplant activity. Since then the number of live donors has steadily fallen.



The availability of a live donor allows 'pre-emptive' transplantation to occur without the requirement to start dialysis. This pre-emptive pathway is associated with the best clinical outcome and is the most cost-effective approach in the renal replacement pathway.

In fact, live donor kidney transplantation is associated with an increase in patient survival of 27 percent at 20 years (over that observed with deceased donors), highlighting that it is a critical component of the wider push for increased organ donation in Australia.

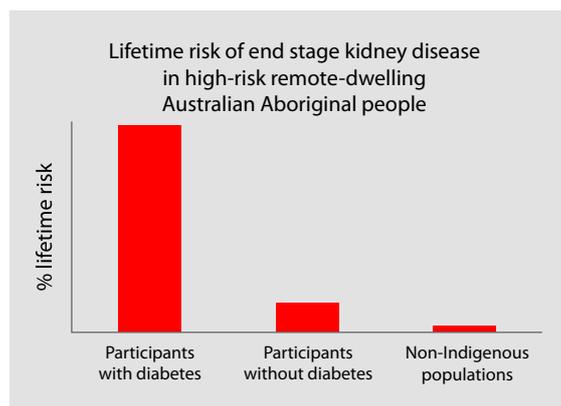
#### *What needs to be done?*

- Consistent National Policy:** Live donation policy should become the responsibility of the Australian Organ and Tissue Authority (AOTA) to better align with existing organ donation activity, draw upon existing staff networks and link with current awareness and education campaigns.
- Improve the System:** Address the issues surrounding surgical shortages and mismatched resources by making live donation a priority, thereby ensuring appropriate theatre allocation, work-up nurses and surgeons for live transplant operations.
- Support Live Donors:** Continue the Live Donor Leave Scheme beyond the current two year pilot, and support it with an Employer Charter and effective communication and education campaign.
- Improve Reporting:** Fund more timely reporting of live donor transplantation through the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) and the Australian and New Zealand Organ Donor Registry (ANZOD). Currently there is a staggering 18 month lag in the reporting of live donations compared to deceased organ donation reporting.
- Lead:** Develop, in discussion with the States and Territories, a standardised policy as to what costs are covered for live donors, thereby overcoming the current inequity which occurs not only between jurisdictions, but between different renal units.
- Educate:** Fund an education program for potential live donors that provides a balanced account of the pathway, process and procedure.
  - Modelled on the existing End Stage Kidney Disease Education Project

## 4. Tackling kidney disease in Indigenous communities

The high prevalence of kidney failure in Aboriginal and Torres Strait Islander people in Australia has been recognised for many years. A recent report by the AIHW summarises and outlines the size and scope of this major influence on Indigenous health and well-being, with an emphasis on the increased prevalence of kidney disease in remote communities<sup>11</sup>.

One telling statistic is that Aboriginal and Torres Strait Islander people make up 2 percent of Australia's population but comprise 10 percent of the dialysis population. Indigenous Australians are almost four times as likely to die with chronic kidney disease as a cause of death than non-Indigenous Australians. Although the cause of the increased prevalence of CKD in Indigenous people is multi-factorial, the impact of diabetes is major and exemplified by the lifetime risk of end-stage kidney failure in Indigenous people increasing from 7 percent to 49 percent, if diabetes is present.



### *What needs to be done?*

- Prevention:** Any action taken to reduce the incidence of CKD in Indigenous people must be a collaborative effort aiming collectively at other chronic diseases such as cardiovascular disease and diabetes. The main focus in CKD prevention is improving lifestyle through better maternal nutrition, reduction of infection rates, healthy diets, reduction in smoking and avoidance of abdominal obesity.
- Treatment:** Regular screening and appropriate treatment need to be further enhanced and promoted as an essential component to a wider approach to 'prevention'. This could be achieved by building upon the existing good work and expanding current MBS funded health checks, subsequent streams of care and medicines arrangements in place for remote areas.
- Education:** funding to address current deficiencies in interactive and easily accessible health educational resources for Indigenous CKD and end stage kidney disease patients. Kidney Health Australia is collaborating with the Menzies School of Health Research in this area.
- Awareness:** Culturally specific health promotion events and programmes that target school-aged children with regard to understanding kidney disease, the importance of substituting sugar laden drinks and adopting a healthy lifestyle.
- Dialysis:** Increased support for the concept of self-care dialysis that enables people from remote communities to get back to their home and to be fully independent. Increased psychosocial support is also needed for all Indigenous people and their families with end stage kidney disease.
- Transplantation:** Establishment of a new approach to kidney transplantation that is culturally acceptable, more accessible and utilizes protocols developed to address the special challenges faced by Indigenous people in coping with immunosuppression and infection.
- Governance and Planning:** The recommendations stemming from the Central Australian Renal Study need to be pursued. This includes State, Territory and Federal Governments agreeing to come together to plan and resource a way forward and overcoming state boundary issues.

<sup>11</sup> Australian Institute of Health and Welfare. Chronic Kidney Disease in Aboriginal and Torres Strait Islander people 2011. Canberra Australia: AIHW; 2011. Report No.: Cat. No. PHE 151.

## 5. Awareness, Education and Self-Management

Life with kidney disease can be an isolating experience. It can be difficult to navigate the health system, to raise awareness of the issues surrounding the ongoing treatment of kidney disease, and to find a way to seek further information.

There is a clear need for a comprehensive kidney education program that focuses on delivering self-management education and increased capacity for people living with kidney disease.

Many of the mechanisms to enable greater self-care by patients already exist – already having been trialled and proven. In many cases, they simply need the recognition and funding to enable them to be rolled out nationally, so that all Australians living with kidney disease can access low cost resources that will empower them to better care for themselves.

### *What needs to be done?*

- **Innovative Engagement:** National implementation of the successfully trialled 'Kidney Kiosk' – an interactive, online touch screen educational tool that allows those living with kidney disease to learn about their kidney disease, treatment, and the best possibilities for self-management.
  - Kidney Kiosk is particularly useful model for demonstrating how to overcome the absence of support for regional and rural Australians living with kidney disease, and could be expanded and applied to other portable devices.
- **Education:** Resources to develop Chronic Kidney Disease Community Education Packages, distributed through Local Health Networks to educate the 'at risk' general public on kidney disease.
- **Self-Management:** Fund an expanded version of the key self-management patient education resource 'Living with Reduced Kidney Function' and an accompanying online resource.
  - The resource offers latest information on CKD self-management
- **Develop and pilot** an Australian version of a successful patient education tool recently published in the United States.
  - This simple two-page written resource significantly improved patient knowledge regarding their CKD when used by health professionals in primary care<sup>12</sup>

Patient using Kidney Kiosk,  
an interactive learning tool.



<sup>12</sup> Wright Nunes J, et al. Pilot study of a physician-delivered education tool to increase patient knowledge about CKD. Am J Kidney Dis 2013;62(1):23-32.

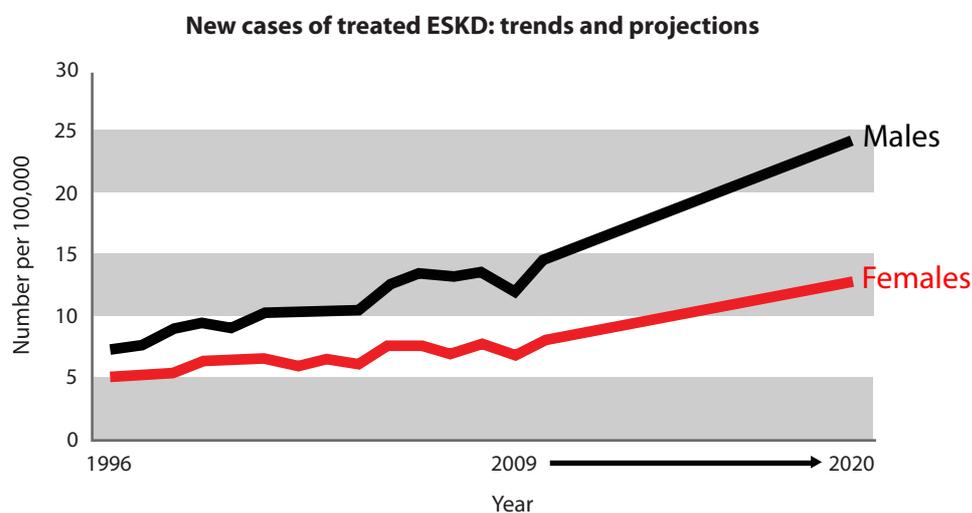
## 6. The need for further research

The relative level of support flowing to kidney research in Australia has never matched the expenditure on kidney disease. This continues to be true with the National Health and Medical Research Council (NHMRC) allocating about 1 percent of its funds to the kidney area when it consumes about 2 percent of the total health budget.

Without improved research outcomes, this cost is simply going to grow.

The recently completed Australian government-sponsored 'Strategic Review of Health and Medical Research'<sup>13</sup> stresses the need for support of the research workforce over the long term. Kidney Health Australia remains one of the main non-government supporters of kidney research in Australia, recently redirecting its program towards the public health arena in an attempt to address a clear shortfall.

Recent advances in the clinical arena offer a new hope – to those living with kidney disease, their doctors and for those administering the health system - and flow directly from research.



For the first time, an effective therapy has been proven for polycystic kidney disease (an inherited condition that accounts for ten per cent of kidney failure in Australia). Significant advances have also been made in understanding the processes causing damage and scarring inside the kidney that result in the progression of most kidney diseases. These advances have the potential to flow into the clinical arena in the next few years and will likely reduce the numbers of patients needing treatment. These advances have occurred as a direct result of the investment in research that has been made. Further advances can only come from increasing this investment.

<sup>13</sup>Strategic Review of Health and Medical Research in Australia. Australian Government Department of Health and Ageing; 2013.

## *What needs to be done?*

Australia needs a national focus on kidney disease, and should appropriately fund kidney research to a level commensurate with the burden on the health system.

The increased funds from this research should be focussed on the following principles:

- **Leading Internationally:** Developing world leading kidney research programs that include programs in prevention and better management of established disease.
- **Kidney Specific:** Ensure that NHMRC and Australian Research Council establish focussed kidney-specific research programs, separate and additional to broader vascular research.
- **Partnership:** Work collaboratively with organisations such as Kidney Health Australia to multiply the impact of available funds.
- **Patient Focussed:** Broad-based research that covers the kidney spectrum but with a special emphasis on patient centred outcomes in the area of kidney failure treatment.
- **Translate and Implement:** Emphasize and facilitate the translation of research findings into clinical practice.

The areas requiring more research include:

**National Plans:** The creation of a national evidence based renal services plan (including a model of care) that focuses on the increased prevalence of kidney failure in the elderly and its adverse impact on quality of life and social status;

**Cost-effectiveness:** Improved cost-effective approaches to the early detection of chronic kidney disease;

**Target Specific Needs:** The development of specific therapies for common kidney conditions such as glomerulonephritis, diabetic kidney disease and vascular disease;

**Pursue Pathways:** The development of therapies that address the pathway of progression to kidney failure through inflammation and scarring that is common to most kidney conditions;

**Vascular Approach:** The impact of CKD on other conditions such as heart disease where CKD is not only an independent risk factor but a major determinant of patient outcome; and

**Patient Centred:** Better understanding of the patient experience leading to a focus on improved patient outcomes as the marker of success particularly in the area of dialysis and transplantation.