Charting a Comprehensive Approach to Tackling Kidney Disease

“Proposals to guide increased risk assessment, support early detection and improve the treatment of kidney disease.”

Kidney Health Australia is a national health care charity with a vision ‘to save and improve the lives of Australians affected by kidney disease.’ As the national peak body, Kidney Health Australia promotes good kidney health through the delivery of programs in education, advocacy, research and support.

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Introduction – The Rising Burden of Kidney Disease

Chronic Kidney Disease (CKD) is a major health problem, and one that is growing. Without greater focus from the Australian Government, there is clear evidence based on current trends that the situation has the potential to worsen. Kidney Health Australia estimates that 1 in 3 Australians are at an increased risk of developing CKD. Approximately 1.7 million Australians – a striking 1 in 10 – over the age of 18 years have at least one clinical sign of CKD. And the situation is much worse for at ‘risk groups’.

Yet to date, CKD has received little attention, particularly when compared to other chronic diseases. The treatment of those with CKD continues to cost governments in Australia approximately $1 billion, per year, and an economic study by Kidney Health Australia estimates that the cumulative cost of treating all current and new cases of end stage kidney disease (ESKD) from 2009 to 2020 is between approximately $11.3 billion and $12.3 billion. It is clear that kidney disease is a measurable cost to the health system, not to mention a considerable cost in 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. The burden of CKD is distributed unequally and unfairly, as evidenced by the high rates of the condition in the lower socio-economic groups and in the Aboriginal and Torres Strait Islander community.

Kidney Health Australia therefore presents this submission with a range of initial suggested actions to help address the increasing burden of CKD and ESKD. As the peak national body representing the needs of those with kidney disease in Australia, Kidney Health Australia is well placed to identify the current policy impediments to improved health outcomes and offer evidence based, sensible and cost effective solutions for consideration by government. First among those is the need to stem the future tide of kidney disease through early detection, supported by primary health care organisations. It is also the most logical location for such an intervention – 83 percent of Australians visit their GPs at least once a year.

Kidney Health Australia advocates on matters relating to the welfare of kidney stakeholders and the delivery of services to people affected by CKD in all its stages. Furthermore, Kidney Health Australia has close ties with consumers, the medical community, renal units around the nation and is a member of the Australian Chronic Disease Prevention Alliance (ACDPA) and the National Vascular Disease Prevention Alliance (NVDPA). Kidney Health Australia is committed to achieving its mission.

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5 To see Kidney Health Australia’s further views on this, please refer to our ‘Submission into the Review of Medicare Locals – December 2013’ at www.kidney.org.au
6 BEACH Report, 2011-12, p.7
through engaging with renal sector professionals and consumer stakeholders in all initiatives and linking with other key chronic illness programs in an integrated way. Kidney Health Australia’s work is carried out in consultation with the nephrological community and with significant input from our national network of consumers.

In its 45-year history, Kidney Health Australia has built a substantial evidence base to support its activities, and strong support from the community to continue to initiate efforts to reduce the incidence and impact of CKD. This submission represents the next key steps in tackling the problem by building on our existing achievements, and is an impetus for continued improvement. The submission presents a package of evidence-based and cost-effective interventions spanning strategic planning, improved early detection, education, the funding of ongoing treatment and organ donation.

The priority initiatives identified in this proposal focus on improving health outcomes, removing barriers to care for people with CKD, and making savings to the national health budget through either low-cost or no-cost initiatives, initiatives that return direct savings to the budget, or those which could be expected to alleviate a strain from the health system over time and improve national productivity. Each initiative addresses an area where there is good evidence that action is needed, and where there are clear potential benefits for people with CKD across the continuum of care.

Furthermore, the call for a new National Chronic Disease Strategy and the creation of a National Renal Pathway originate from Kidney Health Australia’s view that the current fragmented approach to health care funding and service delivery is a significant threat to many current attempts seeking to improve CKD outcomes. Without an overall guiding agreement there is a risk that the more effective and efficient outcomes sought through future reforms may not be achieved.
Summary of Proposals

A number of interventions and strategies are proposed in the attached Budget submission, which are summarised in the table below.

Kidney Health Australia has included proposals to address the full spectrum of the health sector – from strategic planning and early detection, to education and support in the primary care sector, and organ donation. All of the proposals are realistic, designed to be low-cost, no-cost or generate savings and have one principle in common – they are all designed to improve the lives of those with kidney disease through smart, targeted interventions, which seek to support existing efforts and policy.

<table>
<thead>
<tr>
<th>Proposed Policy</th>
<th>Investment</th>
</tr>
</thead>
<tbody>
<tr>
<td>The development of a new National Chronic Disease Strategy and National Service Improvement Frameworks recognising the rising incidence and cost of chronic kidney disease.</td>
<td>Low cost/ No cost - Departmental resources to staff appropriate secretariat.</td>
</tr>
<tr>
<td>A New National Integrated Renal Pathway focussing on improving health outcomes, removing barriers to care for people with CKD, and making savings to the national health budget.</td>
<td>~$250,000 for the development, with savings to flow from implementation.</td>
</tr>
<tr>
<td>Integrated Health Checks to streamline current approaches and promote early detection of those at high risk of developing cardiovascular disease, diabetes and chronic kidney disease and ensure effective, on-going management.</td>
<td>Potentially cost-saving.</td>
</tr>
<tr>
<td>Education to support General Practitioners with the increased detection of CKD in people with diabetes, following the January 2013 decision by Government to include a measurement of kidney function in the diabetes PIP payment.</td>
<td>Low cost ~ $250,000- $500,000, depending on scope agreed by government (scalable).</td>
</tr>
<tr>
<td>Awareness, Education and Self-Management Resources for Patients to address current gaps, assist those in rural and regional Australia and remove a burden on health professionals.</td>
<td>Low cost – each initiative varies and is scalable – from $250,000 to $500,000.</td>
</tr>
<tr>
<td>Improvements to the live organ donor system to better support live donors and complement the Federal Government’s Supporting Leave for Live Organ Donors Scheme</td>
<td>~$1 million, with the project running over 3 years – similar to the Government’s current funded project with KHA.</td>
</tr>
<tr>
<td>Address research funding for kidney disease through focussed priorities</td>
<td>Match the relative cost spent on treating kidney disease.</td>
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</table>
The Cost to the Health System

Approximately 1.7 million Australians - a striking 1 in 10 - over the age of 18 years have at least one clinical sign of existing CKD, such as reduced kidney function and the presence of proteinuria (protein in the urine) or haematuria (blood in the urine). Perhaps even more startling is that 1.5 million Australians are unaware they have indicators of CKD.

In addition, 1 in 3 Australians is at an increased risk of developing CKD. Australians are at increased risk of CKD if they are:

- Are 60 years or older
- Are of Aboriginal or Torres Strait Islander origin
- Have diabetes
- Have a family history of kidney disease
- Have established heart problems
- Have high blood pressure
- Are obese
- Are a smoker

As outlined above, CKD continues to cost governments in Australia approximately $1 billion per year, and the cumulative cost of treating all current and new cases of end stage kidney disease (ESKD) from 2009 to 2020 is estimated to be between approximately $11.3 billion and $12.3 billion. In addition, a study from the UK confirmed the sizable funding required to support treatment for kidney disease highlighting that the National Health Service (NHS) in England's annual spend on kidney care was estimated at £445 million in 2002 (£566 million in 2009-10 prices, or $852 million Australian dollars). Furthermore, the study indicated that program budget analysis by the Department of Health in England estimated that ‘the total NHS expenditure on kidney care, including CKD, at £1.64 billion in 2009-10’ ($2.4 billion Australian dollars).

The nature of kidney disease with its complex co-morbidities dictates that it needs health initiatives to be ingrained across the full spectrum of the health policy making sphere, and done so in consideration with other chronic diseases, such as diabetes and vascular disease. Indeed, diabetes is the top cause of end stage kidney disease in Australia at 36%, while hypertension causes an additional 12% of cases.

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The most recent data from the Australian Bureau of Statistics (ABS)\(^{11}\) shows that kidney failure is a significant cause of death. In 2011, disease of the kidney and urinary tract were the 10\(^{th}\) leading cause of deaths in Australia, with 3,386 deaths\(^{12}\). This represents a 17% increase in deaths from kidney disease since 2002 – it kills more people each year than breast cancer, prostate cancer\(^{13}\) or even road deaths. Furthermore, the ABS statistics for multiple causes of death indicates that diseases of the kidney and urinary tract contributed as a ‘multiple cause’ to the deaths of over 22,000 people in Australia in 2011 – a striking average of more than 50 deaths per day.

\begin{tabular}{|c|c|c|c|}
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\textbf{Sadly there has been a 45% increase in deaths chronic disease since 2000. More people die from diseases of the kidney and urinary tract each year than breast cancer, prostate cancer and even road deaths.} & & & \\
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\end{tabular}

The most recent data that is available from the Australia and New Zealand Dialysis Transplant (ANZDATA) Registry\(^{14}\) shows that 2,543 people started kidney replacement therapy (dialysis or transplant) in 2012. The number of people on dialysis has increased by 4.1% from 2011 to 2012, resulting in 11,446 people receiving dialysis treatment at the end of 2012.

With dialysis costing up to $79,072 for hospital haemodialysis, $65,315 for satellite, home haemodialysis $49,137 and peritoneal dialysis $53,112 (2009 prices), it is clearly an expensive treatment. Current breakdowns indicate that 22% of Australians receive dialysis at a hospital, 29% were dialysing at home and 49% in satellite centres. However, despite the cost effectiveness to government and potential health benefits of home dialysis for the patient, there are significant state-by-state variations, ranging from 37% in NSW to as little as 13% in the Northern Territory. Furthermore, in Australia there is an overall lack of dialysis capacity – with Australia ranking 10\(^{th}\) of 42 countries listed in the incidence of new end-stage-renal-disease patients in 2011\(^{15}\), with the rate of new patients coming onto dialysis programs significantly lower than many of our international counterparts.

Even when averaging out the different modalities and their respective usage, Kidney Health Australia estimates that the average cost of supplying dialysis is still a considerable $65,000 per person (based on 2009 prices), per year. And of course, this does not take into account the lost productivity dividend resulting from these patients either being forced to reduce their work hours, or leave employment altogether. In light of these considerable costs, Kidney Health Australia therefore provides below a number of policy proposals, which together form a comprehensive ‘next step’ for policymakers in the federal government to consider. Kidney Health Australia’s aim in presenting this budget submission is to ensure that funding is being spent as effectively and efficiently as possible within the health system.

\begin{itemize}
\item \(^{14}\) ANZDATA. Australia and New Zealand Dialysis and Transplant Registry 2012 Interim Summary. 2013. \url{www.anzdata.org.au}
\end{itemize}
A New National Chronic Disease Strategy

The current National Chronic Disease Strategy, designed to provide an overarching framework of the national direction for improving chronic disease prevention and care across Australia, is now in need of revision. Agreed at the Australian Health Ministers’ Conference 2005, the Strategy represents a national agenda to encourage coordinated action in response to the growing impact of chronic disease on the health of Australians and to guide a response to the increasing burden on the health care system.

Sitting under the Strategy are supporting National Service Improvement Frameworks covering the health priority areas of asthma, cancer, diabetes, heart, stroke and vascular disease, osteoarthritis, rheumatoid arthritis and osteoporosis. As outlined in the strategy the “Frameworks outline opportunities for improving prevention and care in relation to these diseases, while not prescribing the detail of individual services in the Australian health system”. A key part of the frameworks for the above health conditions was that they are structured to reflect the patient journey, ranging from the reduction of risk, early detection, managing acute conditions, long-term care and care in the advanced stage of the disease.

The case for change
With eight years now having passed since the strategy was developed, Kidney Health Australia is of the view that it is now an appropriate time for an updated Strategy, along with the subsequent frameworks and dedicated action plans be redeveloped.

Since 2005, the health sector has undergone significant reform – covering the entire spectrum of the health system. This change has embodied significant health reform through the National Preventative Health Strategy, the National Health and Health and Hospitals Reform Commission, and the introduction of Activity Based Funding (ABF). For those with chronic diseases, the introduction of Activity Based Funding (ABF) for Hospital Services is of particular impact, as ongoing treatment within the acute healthcare sector represents a way of life. In particular, those with ESKD are required to utilise one of the many modes of dialysis in order to survive until such time as a transplant becomes a possibility - so any changes to the funding, and therefore delivery of these services for ESKD and chronic disease patients, must be reflected within the overarching chronic disease strategy.

Australia’s first National Primary Care Strategy has also since been developed, and more recently the review being announced into Medicare Locals and their future role and responsibility. Specifically, the Primary Care Strategy articulated one of the four key priority areas for change as the “Better Management of Chronic Conditions”, while another was the “Increasing Focus on Prevention”. Both of these key priorities, combined with the additional two priorities of “Improving Access” and “Improving Quality, Safety, Performance and Accountability”. The review into Medicare Locals has articulated that there is a need to ensure that Commonwealth funding supports clinical services, rather than administration. It is our belief that a revised National Chronic Disease Strategy has the ability to recognise the fact that primary care (and the Commonwealth’s investment) can, and should, play a significant role in the detection and ongoing management of chronic disease, including CKD. A stronger, more integrated and focussed primary health care system with an

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16 Australian Health Ministers’ Conference (2005) National Chronic Disease Strategy p.3
improved system of earlier detection of chronic disease can ultimately reduce the health cost and burden on Australia’s health system.

With regard to the current situation surrounding kidney disease, the most recent report from the Australian Institute of Health and Welfare indicates that the incident rate of treated ESKD is projected to increase by nearly 80% between 2009 and 2020. In addition, the proportion of patients to commence treatment with diabetes is projected to increase nearly 20% between 2009 and 2012.\(^{18}\)

The incident rate of treated ESKD is projected to increase by nearly 80% between 2009 & 2020.

These are striking increases, and it is clear they need to be accounted for within the *National Chronic Disease Strategy*, and clear linkages with other key health plans, frameworks and reviews created so that government and the health sector have a roadmap for tackling these increases. The development of a new Strategy will allow for the consideration of any significant changes to the health system enacted through the recommendations made through the Commission of Audit.\(^{19}\)

Furthermore, with the recent release of the Australia Bureau of Statistics ‘Australian Health Survey’, the first national bio-medical survey, there is now an increased dataset to re-assess Australian’s current health status, and in particular the number of Australians at risk of developing chronic diseases. This is particularly important when you consider that the Australian Health Survey identified a strong disconnect between actual health status and perceptions, with over 55% of Australians believing themselves to be in very good or excellent health - despite the fact that nearly two-thirds of Australians are overweight or obese.\(^{20}\)

Finally, a revised approach will also provide the opportunity to align with recent international action in combating chronic disease, including kidney disease. In 2011, the United Nations recognised kidney disease specifically, through Item 19 of the Resolution adopted by the General Assembly on the ‘Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases’, which stated that member states:

“Recognize that renal, oral and eye diseases pose a major health burden for many countries and that these diseases share common risk factors and can benefit from common responses to non-communicable diseases.”\(^{21}\)

This was only the second time in history of the United Nations that the General Assembly has met on a health issue. The meeting was undertaken with the aim of countries adopting a ‘concise action-orientated outcome document that will shape the global agendas for generations to come’.\(^{22}\)

In addition, the Australian Government has been an active participant in the global non-communicable disease (NCD) community and the development of a global NCD campaign, Global Monitoring Framework and Global Action Plan. This international leadership is seeking to develop a

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18 Australian Institute of Health and Welfare (2011) *Projections of the incidence of treated end-stage kidney disease in Australia 2010-2020*  
19 Kidney Health Australia’s submission to the National Commission of Audit can be found at [www.kidney.org.au](http://www.kidney.org.au)  
21 [Political Declaration of the high-level meeting of the General Assembly on the prevention and control of the Non-communicable diseases (2011) available:](http://www.who.int/nmh/events/un_ncd_summit2011/political_declaration_en.pdf) p.3  
comprehensive global approach to tackling the leading causes of mortality and morbidity across the globe, and should therefore be complemented by a revised and more comprehensive national chronic disease strategy, that includes appropriate funding to implement lasting change.

**Budget Proposal for Consideration**

Noting the fact that kidney disease is linked to most of the other chronic diseases and spans the full spectrum of the health continuum - from health promotion and early detection to treatment in the acute sector - a revised *National Chronic Disease Strategy* should again consider chronic disease from the point of prevention through to ongoing management, while taking into account the above factors.

As page 3 of the existing strategy highlights “*A continuum of chronic disease prevention and care interventions corresponds to different population groups – people without disease, those at risk of disease, and people currently coping with chronic disease.*” As outlined in the introduction to this submission the economic impact of CKD, combined with the rising and projected prevalence of the disease means that concrete action to tackle rising rates of chronic disease, while better supporting those already with chronic disease, are in need of review. Specifically, more needs to be done to prevent, slow the progression of, and delay the onset of CKD through greater recognition within a revised strategy, but also the creation of a dedicated Framework for CKD, matching those already developed for heart, diabetes and stroke.

The Department of Health commit the necessary resources to commence the development of a new *National Chronic Disease Strategy* to address the changing nature of chronic disease in Australia, and develop new associated Frameworks, including a new *Framework for Kidney Disease* in recognition of the rising prevalence and impact of chronic kidney disease on the Australian population. It should be more action-orientated to better reflect the global chronic disease strategy and targets adopted by the World Health Assembly in 2013.

In the development of a new *National Chronic Disease Strategy*, Kidney Health Australia would advocate for similar development processes as employed last time, that is:

- The establishment of a reference group to provide guidance to the Strategy’s development
- The establishment of a working group of individuals representative of both the policy and medical community
- Strong collaboration with key stakeholders, such as the peak chronic disease, workforce and indigenous health bodies
- That appropriate funding be put aside in future years to fund the changes outlined in a new comprehensive *National Chronic Disease Strategy*

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23 Australian Health Ministers’ Conference (2005) *National Chronic Disease Strategy*, p.3
A National Integrated Renal Pathway

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 population24. There has been a 45% increase in deaths from chronic kidney disease since 2000. Kidney-related disease kills more people each year than breast cancer, prostate cancer or even road traffic accidents.

Despite costing governments in Australia approximately $1 billion per year25, 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 case for change

Kidney Health Australia, the State based Renal Health Networks and the Australia and New Zealand Society of Nephrology believe that there is much that can be done to improve the early detection - and more efficient treatment - of kidney disease to help stem the predicted tide of new cases of end stage kidney disease (ESKD), putting downward pressure on the usage of high cost dialysis treatment.

There are deeply entrenched problems with the planning and delivery of renal replacement services throughout Australia. There is an overall shortfall in the capacity of dialysis services resulting in:

- A lack of choice for many people facing dialysis leading to the allocation of people to a type of dialysis that is not their preferred option and is often cost inefficient
- A marked variation by State in the uptake of home dialysis programs, despite this treatment modality being associated with lower cost, reduced need for specialist personnel, improved quality of life, flexibility in quantum of dialysis treatment and probable increased survival
- A low number of people being treated on dialysis programs by International comparison
- A marked variation by State in the demographics being offered dialysis therapy

In addition it is noteworthy that for a high cost therapy, largely performed in public health facilities, there is a surprising lack of timely public accountability of dialysis activity and no systematic auditing of adequacy of care, safety or patient outcomes. There is a need for smart, evidence based management and future planning for delivery of dialysis services.

Previous and ongoing jurisdictional activity

These jurisdictional plans are characterised by variable uptake and implementation, and have resulted in mixed outcomes.

24 AIHW 2011. Projections of the incidence of treated end-stage kidney disease in Australia, 2010-2020. Cat. no. PHE 150. Canberra:
25 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
• NSW: Published Renal Dialysis Service Plan to 2011 in 2007
• Victoria: Published a Renal Directions Discussion Paper in 2013.
• SA: Recently published a paper on Initiation of Dialysis but has not developed a formal Renal Plan.
• Qld: Published a Renal Services Plan in 2008
• Tasmania: Published a Renal Services Plan in 2010
• WA: Published a Model of Care for Renal Services in 2006
• ACT: Published Renal Health Services Plan in 2010
• NT: Published Renal Services Strategy in 2005

Previous and ongoing national activity
• National: Federal Government published National Chronic Disease Strategy and five supporting National Service Improvement Frameworks in 2005
• National: Kidney Health Australia published National CKD Strategy in 2006

The 2006 National CKD Strategy was based on wide consultation with stakeholder organisations and individuals, and an extensive review of the national and international CKD literature. This process identified 18 National Priority Actions across the CKD continuum of care, but was not funded to develop the necessary implementation plans.

Budget Proposal for Consideration

The National Integrated Renal Pathway focuses on improving health outcomes, removing barriers to care for people with CKD, and making savings to the national health budget.

A National Integrated Renal Pathway would:
• leverage off the previous and ongoing jurisdictional activities
• accomplish equity
• improve clinical and psychosocial outcomes
• provide cost savings for federal and state governments

It is critical to establish an agreed, robust, evidence-based pathway to manage people along the continuum of CKD. The advantages of a National Integrated Renal Pathway are the opportunity to develop recommendations on key areas of national importance such as early detection, role of primary care, choice of dialysis location and transplant options. If implemented, the likely recommendations in a National Integrated Renal Pathway would be cost effective for government.

Framework for a National Integrated Renal Pathway would be:
• Evidence-based
• Patient-centred
• Cost-effective
• Able to be resourced and implemented
• Provide governance, including measuring, monitoring, reporting, and lead to quality improvement
Components of the National Integrated Renal Pathway

The National Integrated Renal Pathway would focus on key areas such as:

- Early detection of CKD and closing the gap in appropriate management in primary care
- Evidence based interventions being applied appropriately to all those identified to have CKD
- Strong focus on patient education and self-management at all stages of CKD
- A smooth entry into renal replacement therapy with an emphasis on an educated patient making an informed choice
- A policy of home dialysis or pre-emptive transplantation first
- The role of supportive care for people on either the dialysis or non-dialysis pathway

The National Integrated Renal Pathway would:

- Contain an environmental scan (events, trends, issues, expectations) and identify opportunities for improvement
- Embrace workforce issues and recommend upon minimum ideal staffing levels with an emphasis on the need for expanded allied health capacity in the kidney arena

The development of a National Integrated Renal Pathway with its expected recommendations would serve little purpose if there is not engagement with the Commonwealth and State Governments from the beginning. Failure to get their support would mean the project had limited likelihood of having any impact on the kidney sector.

Therefore, the ideal approach to this project would be to put together a proposal for the consideration of AHMAC who would then fund and contract the work. Kidney Health Australia would be a potential tenderer for this contract. An AHMAC supported project carries with an increased likelihood of ownership of the findings, and thus would lead to successful implementation.
A New Integrated Health Check in Primary Care

This proposal advocates for the introduction of an integrated health check in general practice to assess for risk of cardiovascular disease (CVD), type 2 diabetes and chronic kidney disease with coordinated management of those diagnosed with chronic disease through Medicare Locals. This is a view also shared by the National Heart Foundation and the Stroke Foundation, and is likewise represented in their budget submission.

The case for change
Cardiovascular disease (CVD) is Australia’s largest killer, causing more than 46,000 deaths each year, almost one-in-three deaths. It accounts for 18% of the overall burden of disease in Australia and is the most expensive disease group in terms of direct healthcare costs, at $7.9bn a year or 11% of recurrent direct health care expenditure.

CVD also has a strong relationship with other significant chronic diseases, in particular type 2 diabetes and, of course, chronic kidney disease - the impacts of which are outlined extensively in this submission. Because they share risk factors, underlying causes and disease mechanisms, these major chronic diseases often occur together. For example, it is estimated that more than 400,000 Australians have both CVD and diabetes, and as outlined above, 35% of those who progress to ESKD have diabetes. Importantly, effective prevention and management of one condition can lead to reduction in the risk of related diseases.

Unfortunately, too many people are at high risk of developing these diseases, or living with them and going unrecognised, leading to avoidable premature death and disease at significant social and economic costs to the nation.

Early detection and ongoing management of these chronic diseases is the key to reducing the number of CVD events (such as heart attacks and stroke) occurring each year while also reducing the incidence of diabetes and chronic kidney disease.

But the current suite of government-funded health checks are not effectively identifying those at risk primarily because of low access rates, non-integrated approaches to CVD risk assessment and the absence of a national program to support better management of risks for CVD and related diseases, like type 2 diabetes and kidney disease.

In 2009, the Australian Institute of Health and Welfare published a framework for monitoring the prevention of vascular and related disease. The framework cited evidence that existing vascular and related disease assessment and management programs had limited uptake, and were not well integrated or promoted as part of a national preventative health system. It revealed that less than a quarter of those over 75 years, and only 6% of those aged 45-49, were accessing regular health checks.
These figures are alarming, especially given the high prevalence of a number of significant risk factors in the community, including overweight/obesity, high blood cholesterol and high blood pressure. Recent data shows that while some risk factors, such as tobacco smoking, are in decline (though still highly prevalent), other risk factors are becoming increasingly prevalent or remain at very high levels.

The Australian Health Survey (2011-12) reveals that 63% of Australian adults are overweight or obese, up from 56% in 1995. More than 60% of men had a waist circumference that put them at an increased risk of developing chronic disease, while 67% of women had an increased level of risk.31 The survey also shows that just over three million adults had measured high blood pressure.32 A coordinated approach is required to increase awareness of individual vascular and related disease risk, to provide high quality assessment of individual risk and to provide appropriate interventions to support risk management.

**Budget Proposal for Consideration**

The current suite of government-funded health checks are not effectively identifying those at risk of low access rates, non-integrated approaches to CVD risk assessment and the absence of a national program to support better management.

Kidney Health Australia proposes a high quality assessment of disease risk through the collection of data on major risk factors through simple questions, tests and measurements. Comprehensive vascular and related disease risk assessments and ongoing preventative care for those people identified to be at higher risk should occur in a primary care setting, including that of general practice and Aboriginal medical services.

The assessment should include recognised measures to assess risk including:

- A CVD risk assessment (an absolute risk assessment where appropriate and consideration as high risk if clinically indicated)
- AUSDRISK (+/- blood glucose tests)
- Serum creatinine and urinary albumin

Assessment and classification of moderate and high-risk individuals should result in provision of medical interventions to reduce individual risk and referral to quality-assured lifestyle modification programs. GPs would prescribe necessary medication and refer people at risk to lifestyle interventions that could be delivered through a range of community settings. Medical interventions could include drug treatments for high blood pressure and high blood cholesterol.

Lifestyle interventions could include: smoking cessation services; weight management or exercise and behaviour change programs. Lifestyle modification programs incorporating weight reduction, healthy eating and physical activity are currently available for people at high risk of type 2 diabetes and could be broadened to include people who may be at increased risk of vascular diseases. Establishment of a systematic process for identification of risk of CVD, diabetes and kidney disease will increase referrals to such programs, increasing their efficiency.

A first step should be the introduction of national targets and indicators to help primary care organisations directly meet the Australian Government’s health policy objectives of reducing the

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31 Australian Bureau of Statistics (2012) *Australian Health Survey: First Results, 2011-12*

32 Australian Bureau of Statistics (2012) *Australian Health Survey: First Results, 2011-12*
burden of chronic disease and avoidable hospital admissions. Kidney Health Australia has argued primary health care organisations should be tasked with:

- The early detection of people at risk of and with chronic disease and ensuring they are effectively managed
- The better integration of effective lifestyle modification programs with primary care providers
- With ongoing education to support improved clinical outcomes.

Consolidating the current existing primary health care approaches into an integrated health check will help GPs determine a person’s absolute risk of a cardiovascular event and the most appropriate preventive measure for people who are at risk, but not yet showing symptoms, of disease.

This will have potentially significant benefits to those at risk as well as to the healthcare system. The direct health cost of CVD (currently $7.9bn a year) and of CKD could be contained with early identification and management of those at high risk before they develop disease, particularly for those aged over 45. Anticipated benefits include systemic efficiencies, substantial cost savings and reduction in chronic disease related hospitalisations. In addition, the proposal supports a number of priority areas within the National Primary Health Care Strategy 2010. The need to develop an integrated health check has been recognised in the UK, where the British Government’s Putting Prevention First program (commenced in 2009) is based on vascular checks for people in middle-age.

The Australian Government should fund an integrated health assessment program linking assessment, prevention, coordinated care and management which encompasses the following elements:

1. **Assessment**: Assessment of risk factors, including kidney function, diabetes status (using AUSDRISK or blood glucose testing in high risk individuals), and the calculation of an absolute risk score assessment for stroke and heart attack risk.

2. **Prevention**: Prevention for those at high risk of type 2 diabetes or with high absolute cardiovascular disease risk or high kidney disease risk. Those identified at high risk of chronic disease in the assessment phase are referred to appropriate community-based lifestyle modification programs.

   It is proposed that chronic disease care coordinators should be funded to assist with care coordination and provision of self-management support. There is good evidence that this coordination role has a positive impact on patient outcomes, is best performed by a non-GP care coordinator and leads to a significantly lower use of health services. To enhance the capacity of the chronic disease care coordinators to deliver the range of activities required, a primary health care provider network should be established to support the coordinators and other primary health care providers to promote interdisciplinary communication, networking and collaborative practice.

3. **Management and treatment**: Pharmacotherapy and lifestyle advice are among the management and treatment tools for those at high risk of developing cardiovascular and related diseases.

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Education to Support the Increased Detection of CKD in People with Diabetes

With the decision by the Federal Department of Health to include a measure of kidney function as part of the GP Practice Incentive Payment (PIP) for the annual cycle of care for people with diabetes, the below proposal outlines an education program to support GPs in undertaking this new work.

The case for change

Population surveys have consistently shown that clinical evidence of CKD is present in about 11% of all adults. The recent Australian Health Survey for the first time asked the question “do you have kidney disease?” Only 0.8% responded “yes”, indicating that only one in 12 of those who had CKD was actually aware of it. The low rate of awareness of CKD, particularly when compared to other chronic conditions, is highlighted in this figure and indicates a great deal more is required to be done in terms of education and awareness.

The last decade has seen the development of an International definition of CKD, which has led to a staging scheme with clinical action plans aligned to each stage. The recently amended staging scheme emphasises the need to ascertain the underlying diagnosis, establish the degree of kidney dysfunction and assess the presence of protein in the urine. This new staging scheme offers improved correlation with kidney and cardiovascular outcomes.

Yet a recent report indicated that in rural general practice in Australia, there are significant shortfalls in the recording of kidney function and the recorded prescribing of appropriate kidney protective therapy. Furthermore, the AusHeart study recently concluded that CKD is common, significantly under-recognised and under-treated in primary care.

Kidney Health Australia has recently distributed the 2nd edition of its guidance booklet “Chronic Kidney Disease – Management in General Practice” to all practitioners in Australia, in part to address this shortfall. This booklet captures the latest changes to the staging and management recommendations for people with CKD. This initiative was developed by the Kidney Check Australia Taskforce (KCAT) program that Kidney Health Australia has conducted for the last 10 years. The program, the only one of its kind in Australia, seeks to educate health professionals in primary care.

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on the advances in knowledge and management of CKD. This program with limited funds has focussed its educational effort on face to face workshops, on-line learning and written material.

The broader Kidney Health Australia vision has been that all people identified to be at high risk of having CKD should be opportunistically offered a kidney health check (blood test, urine test and BP check) in primary care on a regular basis. Given that it has been estimated that 85-88% of all adults attend their GP each year, this approach has the potential to be both effective and affordable. Yet, despite the obvious mechanism to carry out a kidney health check through such cost effective means by consolidating with existing GP consultations, Australia remains a long way from achieving this vision, given the facts outlined in this submission.

In an effort to address this, one special focus of GP education for Kidney Health Australia have been people with diabetes. Studies have shown 50% of people with type 2 diabetes in general practice will have CKD, and 47% of all new people commencing dialysis in 2010 had diabetes (35% of the total had diabetes as the coded cause of their kidney failure). Projections indicate that the number of people with kidney failure secondary to diabetes will double in the next decade and will account for almost all growth in Australian dialysis numbers (Figure) 39.

In recognition of this alarming state, measurement of kidney function has just been agreed (January, 2013) to be included in the annual cycle of care, which forms part of the documentation of the practice incentive payment (PIP) for people with diabetes in primary care. For this initiative to realise its full potential, Kidney Health Australia advocates an education program be delivered to GPs to support them in carrying out this new function under the PIP payment.

Budget Proposal for Consideration

A recent report indicated that in rural general practice in Australia, there are significant shortfalls in the recording of eGFR and the recorded prescribing of appropriate kidney protective therapy.

Kidney Health Australia, through its existing KCAT project is well positioned to roll out a national education program to support the Government’s recent policy change to introduce a measure of kidney function as part of the diabetic annual cycle of care PIP payment, and do so cost effectively and with minimal start up time.

By leveraging off the existing program, Kidney Health Australia proposes rolling out an education program to GPs, to be delivered over two years, commencing on 1 July 2014. The program would deliver face to face workshops at each of the 61 Medicare Locals. These face to face workshops would be one-to-two hour workshops using a local nephrologist as the facilitator, and would be accredited by the Royal Australian College of General Practitioners (RACGP) and offer a high quality, evidence-based presentations backed up with hardcopy takeaway resources for participants. The program would have specific learning objectives for GPs, specifically:

- Knowing the eight major risk factors for CKD
- Knowing how to measure kidney function and interpret the results
- Being able to outline the optimal management of diabetic kidney disease
- Gaining a better appreciation of the need to screen high risk individuals for CKD
- Being able to implement a practice based system to perform a kidney health check for patient at increased risk of CKD

In addition, the program would involve developing a supplement to existing on-line learning modules on CKD and diabetes (the original of which was launched in February 2013 through ‘Think GP’.

The Kidney Health Australia’s publication “CKD – Management in General Practice”, already well recognised and used within primary care will be updated to include a specific section on the annual cycle of care for people with diabetes. This will also be supplemented through a laminated factsheet on the changes to the annual cycle of care and mailed to all general practitioners as an attachment to the Australian Family Physician publication (or equivalent).

By leveraging off Kidney Health Australia’s existing publications and through the delivery in Medicare Locals the total cost could be limited to approximately $260,000 for low level intervention but could be scaled up to $500,000. This represents a relatively small cost to support the Australian Government’s decision to include a measure of CKD as part of the existing PIP payment. The breakdown would be as follows:

- Workshop – Development of Materials - $10,000
- Running of the workshops ($3,000 each at each Medicare Local) - $183,000
- Development of an online supplement - $10,000
- Amendment of Kidney Health Australia’s booklet and distribution - $7,000
Awareness, Education and Self-Management for Patients

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. The below proposals are modest in cost but designed to be significant in impact and utilise existing and proven models.

The case for change
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.

There is also increasing demand for an enhanced service to provide information, clarify issues and help people through the emotional journey of living with kidney disease, and understanding its impact on lifestyle and family with practical information and pathway suggestions. The health care system is increasingly strained in providing health and medical services to the growing number people with chronic illness, and information provision and patient understanding can often fall by the wayside.

A medical appointment offers only a small window of opportunity to discuss complex health queries and as a result, people often leave their health provider seeking additional information and support. Kidney Health Australia has the only service that exists in Australia that has understanding of, or offers support for, kidney disease and currently responds to more than 2000 enquiries a year, without promotion of the service – a 10% growth on 2012. The service, called the Kidney Health Information Service (KHIS) provides information, support and referral advice relating to kidney health. It is often the case that the KHIS service is the first point of human contact after diagnosis of kidney failure, helping people through the emotional journey of understanding kidney disease and its impact on lifestyle and family with practical information and pathway suggestions. Noting that you can lose 90 percent of kidney failure before symptoms appear, the realisation that they will now require dialysis for the remainder of their life (or until such time as a transplant) can be a significant shock.

Many of the mechanisms to enable greater self-care by patients 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.
Budget Proposal for Consideration

Kidney Health Australia has prepared the below recommendations to assist in supporting patients, their carers and their families through the journey of living with kidney disease. Each of these proposals is low cost and designed to work to address areas where, based on our observations, current support is lacking.

The first would involve the expansion of an already successfully trialled interactive resource – the ‘Kidney Kiosk’. The kiosk is 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 a 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 be applied to other portable devices. Using online technology, it is cheap, scalable and updatable. Kidney Health Australia estimates that such a service could be rolled out nationally, online, through dedicated national project management, content creation, production and through leveraging off existing partnerships for $200,000. This would place the content online, so would not include the hardware costs – meaning each hospital or health service provider is not locked into purchasing specific hardware, but rather could determine the best mechanism to suit their circumstances.

Secondly Kidney Health Australia would recommend the development of an education resource – specifically a Chronic Kidney Disease Community Education Package, which would be distributed through existing networks such Local Health Networks to educate the ‘at risk’ general public on kidney disease. The goal would be for this education to then encourage those at risk to visit their GP to ascertain their kidney status, thereby contributing to both earlier detection, and a reduction in health costs arising from late detection. This could be packaged with training for volunteer speakers and has the capacity to provide essential regional and rural coverage. The total cost, including a fulltime resource, content development, production and evaluation would only be $385,000 for a program to run nationally. This could be further supplemented by funding and developing a pilot of a successful patient education tool recently published in the United States for patients once they are identified as having CKD. This simple two-page written resource significantly improved patient knowledge regarding their CKD, when used by health professionals in primary care. The cost for this resource would be modest - $250,000 for the development and $50,000 per year for five years for distribution costs.

Thirdly, Kidney Health Australia would recommend enhanced telephone support and information, by expanding our national KHIS to respond to greater call volumes and provide understanding, support, information and pathways for people living with kidney disease. The current service is beyond capacity and has no ability for additional call volume – a significant concern noting the predicted increase in kidney disease. CKD is increasing in prevalence and research indicates there is a critical level of undiagnosed disease in the community. As promotion of risk factors increase, we anticipate more awareness and diagnosis resulting in increased demand on the service. Upgrading the service will ensure it is more efficient and responsive and will more effectively meet stakeholder needs, particularly those living in rural or regional Australia. Future demand could be met by an additional dedicated staff member, appropriate training, a digital online education resource and a modest upgrade to the current telephony system for $250,000.
The Australia Government provide a small amount of funding to the following education and support mechanisms to address identified gaps in the patient experience, improve earlier detection, patient understand and reduce burden on the health system, particularly GPs.

- Fund an online expansion of the ‘Kidney Kiosk’ initiative – helping those with kidney disease learn about their condition and assist in understanding self-management options ($250,000).
- Development of an educational resource targeted at those ‘at risk’ of developing kidney disease and distribute through existing networks, such as the Local Hospital Networks, complemented by a volunteer speaker program ($385,000).
- Development of an educational resource, modelled off an already successful US trial to improve patient knowledge regarding their CKD and aid their GP in communicating these issues ($500,000 over five years).
- Fund an expansion of the Kidney Health Information Service to meet current and future demand and address an area where there is currently a significant gap in information provision ($250,000).

More detailed costings for each of these initiatives can be provided at any stage.
An improved Live Organ Donor System in Australia

Live donor kidney transplantation (LDKT) peaked in 2008 when it accounted for 44% of the total transplant activity. The availability of a live donor also allows “pre-emptive” transplantation to occur without the requirement to go onto dialysis. This pre-emptive pathway is associated with the best clinical outcome and is the most cost-effective approach in the renal replacement pathway. LDKT is associated with an increase in patient survival of 27% at 20 years (over that observed with deceased donors).

The case for change
The work undertaken by the Australian Organ and Tissue Authority (AOTA) over the last 4 years has seen a substantial and sustained increase (25% increase over 4 years) in the number of deceased donors being made available for kidney transplantation. Currently, despite having some of the highest success rates for organ transplantation in the world\textsuperscript{40}, Australia’s rate of deceased organ donation has failed to keep abreast with demand for transplantation\textsuperscript{41}. Indeed, the number of deceased organ donors will never meet the demand, no matter how efficient the retrieval process - therefore there is a need to increase the rates of kidney transplantation by increasing the number of living donors.

The increase in deceased donations has however not been accompanied by an increase in the total number of kidney transplant operations due to a co-incident 33% fall in the number of live kidney donors in the same time period. The reasons for the fall in the live donor numbers are not evident and were the subject of a review by the Australian Government in late 2013, the outcomes of which are believed to be forthcoming.

The latest figures, released on the 29\textsuperscript{th} of January 2014 highlight that this downward trend is finally reversing, all be it very slowly – with an increase of 12 on last year’s result. Kidney Health Australia believes that this is a result of the introduction of the ‘Supporting Living Donors Leave Schemes’ in July 2013, and our ongoing media, communication and education efforts.

However, there are a number of issues Kidney Health Australia believes can be considered as further ‘contributors’ to be undertaken to address the performance of live donation in this country. The rate of uptake of live donor kidney transplantation varies significantly between units, regions and States in Australia. The reason for this variation (documented to vary tenfold between units) is not well studied but is believed to largely reflect the attitude of health professionals to live donor transplantation and the variable resourcing of units with staff such as a dedicated LDKT workup nurse. There is a significant deficiency in education and communication materials for both the medical profession and the community regarding live donation – a deficiency that becomes even starker.

\textsuperscript{40} National Clinical Taskforce on Organ and Tissue Donation, 2008, \textit{National Clinical Taskforce on Organ and Tissue Donation Final Report: Think Nationally, Act Locally}, Commonwealth of Australia, p. 77.

when compared to the efforts put into deceased organ donation. While the issue of deceased organ donation is being handled through a dedicated agency (with extensive communication and education materials, a national register and a network of dedicated DonateLife staff), no such support exists in the area of live donation. Even the government’s ‘Supporting Leave for Live Donors’ Scheme is run by the Department of Health, not AOTA, and has no communication, awareness raising or education funding to support it – despite this being essential to its ongoing success.

The Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) (together with its “sister” registry, the Australian and New Zealand Organ Donor Registry (ANZOD)) have the responsibility for reporting on the number and characteristics of live donor kidney operations. In contrast to the remit for ANZDATA/ANZOD to report on deceased donor activity on a monthly basis by the 2nd Monday of each month (thereby ensuring that all stakeholders can monitor performance effectively) there are no such requirements in the live donor area.

Budget Proposal for Consideration

Currently, despite having some of the highest success rates for organ transplantation in the world, Australia’s rate of deceased organ donation has failed to keep abreast with demand for transplantation. Live donation will for the foreseeable future be an essential component of broader organ donation efforts.

Firstly, Kidney Health Australia is of the view that Live Donation policy should be the responsibility of the Australian Organ and Tissue Authority (AOTA). The establishment of AOTA in 2009 and the consequent changes to deceased donor procurement centring on the organisation’s engagement with hospitals, the establishment of the DonateLife network, public communication, education, awareness, activities, events and engagement with civil society, including through the Advisory Council, has led to significant increases in the deceased donation rate.

In addition AOTA are responsible for the Australian Paired Kidney Exchange Program (AKX) ‘an initiative of the Organ and Tissue Authority to increase the options for living kidney donation’42 – a scheme which is clearly a living donor policy in action. However, this means there is a clear division and split within the way in which live donation policy is being administered and run in this country, with the Department of Health taking on a large part of the policy role and the leave scheme. By placing this aspect of organ donation under AOTA it would better align it with existing activities and therefore create an economical and efficient mechanism for moving this issue forward, by leveraging off all the work and structures already in place.

It is envisaged that AOTA would be charged with establishing standard clinical protocols (including guidance about clinical suitability of would be live donors), minimum performance criteria, education material for staff and patients and the responsibility for reporting the rate of, and the long term follow-up of, live donors.

The limited education and communication materials around live donation is in part driven by the absence of high quality education material that informs new or existing dialysis patients about LDKT in a positive, yet balanced manner. Noting the strong focus by AOTA on improved education, marketing and awareness activities for organ donation, it could be considered both economical and efficient to include information regarding live donation in current donation communication and donation efforts. Such channels exist to inform key target markets regarding donation, such as patients, carers, medical professionals, renal networks, clinics and the broader kidney network. Such a strategy could also leverage AOTA’s already existing presence at key organ donation related

events, social media campaigns and online activity. Kidney Health Australia is currently developing high quality patient education material in the area of dialysis (through an Australian Government grant) and a similar initiative is needed in LDKT. Furthermore and as per past submissions, we call on the Government to fund communication activities to support the live donor leave scheme, including the creation of an employer charter which could be signed by peak employee and business organisations.

Secondly, Kidney Health Australia is of the view that there is a strong case for Australia to document the long term outcome of live kidney donation. Live kidney donation has generally been documented as a low risk, although recent overseas studies have highlighted that there may be some risks to the donor. The risk in the long term can be significantly impacted by the tendency in recent years in Australia to relax the live kidney donor acceptance criteria to include some donors with obesity, pre diabetes and hypertension. It is clear that living donation forms an essential part of broader Australian organ donation efforts, yet currently live kidney donor follow-up is not mandated - and in many areas is left in the hands of the primary care system.

Such an outcome could be improved through an expanded live kidney donor registry. Australia has a registry, established by ANZDATA in 2003 to accomplish the purpose of long term follow-up of Australian donors, and suggested annual follow-up data recording. Participation in this registry is on the basis of opting in with a formal consent process in place. However, the existing register contains no assessment of quality of life, it is not systematic, and experiences significant drop off in follow-up – the loss to follow-up percentage is over 70%. In short, it is both inadequate and incomplete.

Through mandating improved follow-up, the registry should take into account an assessment of the ‘quality of life’ of the donor over the long-term, post-surgery. This would also include bringing back remotely based donors for a central follow-up through providing a mechanism to pay the physician. Kidney Health Australia would suggest such follow up could be limited to a 5 yearly period, thereby not creating an excessive cost. Furthermore, by injecting a small amount of funds into the registry and a physician payment mechanism, it should also be possible to make a system that is physician independent – something critical to ensuring follow up over the longer term (20-30 years).

Thirdly, there is a need to address the issues surrounding surgical shortages and mismatched resources – stemming in part from the Federal / State divide between organ donation and transplantation. Kidney Health Australia has been made aware of direct reports from renal units where there have been issues of:

- A shortage of surgeons resulting in the need for interstate short term recruitment
- A shortfall in theatre allocation to LDKT, resulting in ‘gating’ the maximum number of operations
- A lack of dedicated LDKT workup nurses, resulting in delays and inefficiencies

Kidney Health Australia calls on the Australian Government to address this issue through an AHMAC driven process of review.

Finally, there is a need to bring live donation reporting up to the same level as we currently see for deceased reporting. As outlined above, live donation reporting is usually many months after the annual close of the database before any report is issued. This means that it is often 18 months behind in documenting monthly activity. This seriously impairs any timely analysis and the opportunity to address problems impacting live donation. Kidney Health Australia suggests that AOTA be required (as the funding body for ANZDATA/ANZOD) to be given responsibility for creating
and monitoring reporting timelines. A modest increase in resources for these Registries would be required to allow additional staff time to be allocated to this process, but would remove the stark disparity between deceased and living organ donation reporting.

Kidney Health Australia believes that in order to improve the live organ donor system in Australia the following policy responses should be considered:

- Live Donation policy, including the Supporting Leave for Live Donors become the responsibility of AOTA. This will allow:
  - Increased communication, awareness and education to be efficiently leveraged off existing, funded activity and networks, such as the DonateLife network;
  - Consistency in messaging and policy development, all aimed at improving the overall organ donation rate in Australia
- Addressing, in conjunction with the States to address clinical and resource constraints that currently impede live donations.
- An improved live donor registry to provide for regular, systematic follow-up of live donors to assess their quality of life, describe practice patterns of living kidney donation in Australia, describe the relationship between donor factors and recipient outcomes and monitor risks associated with kidney donation.
- Remove the significant delay that currently exists in live donation reporting and make it consistent to bring it more in line with deceased donation reporting, and therefore allow timely analysis and the opportunity to address any problems identified.
The need for further research

Recent advances in the clinical area offer a new hope – to those living with kidney disease, their doctors and those administering the health system – and these benefits flow directly from research. For example, 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), a direct result of research. 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. Further advances can only come from increasing this investment.

The case for change

The relative level of support flowing to kidney research has never matched the expenditure devoted to treating 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’44 Report 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.

Budget Proposal for Consideration

*From Homer Smith "From fish to philosopher" (1953)*

"Recognizing that we have the kind of blood we have because we have the kind of kidneys we have, we must acknowledge that our kidneys constitute the major foundation of our philosophical freedom. Only because they work the way they do has it become possible for us to have bones, muscles, glands and brains. Superficially, it might be said that the function of the kidney is to make urine; but in a more considered view one can say that the kidneys make the stuff of philosophy itself."

Firstly, Kidney Health Australia believes that Australia needs a greater 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

Kidney Health Australia believes a modest increase in Research funding could be targeted at the following areas to have greatest, practical effect:

- 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.