OUR VISION

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

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

• 1 in 3 Australians is at an increased risk of developing chronic kidney disease.
• 10,998 people were receiving dialysis treatment at the end of 2012.*
• 825 kidney transplant operations were performed in Australia in 2012.*
• At the end of December 2012, 1,080 people were waiting for a kidney transplant in Australia.

*latest statistics available
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The work of Kidney Health Australia as the national peak body is critical to raising public and professional awareness of the need for early detection and prevention of kidney disease and its complications and importantly supporting those already on dialysis, their families and carers. In 2012 we made significant steps forward in a number of areas as outlined in the Chief Executive Officer’s report. Importantly 2012 was a milestone year in terms of financial performance without which the organisation could not deliver its programs and services.

In mid-2012 the Board met to develop the Kidney Health Australia 2020 Strategy which embodies a set of fundamental goals designed to save and improve the lives of Australians affected by kidney disease.

Our business strategy is built around the delivery of support to Australians with kidney disease whilst ensuring a public focus on early detection and prevention through education, advocacy, research and support.

**Importantly 2012 was a milestone year in terms of financial performance without which the organisation could not deliver its programs and services.**

Our 2020 goals take into account the challenges faced by the kidney sector for health policy recognition of kidney disease as well as the challenges and opportunities faced by Kidney Health Australia within the current economic operating environment where competition for scarce Government and corporate resources is at a peak.

Kidney Health Australia’s national strategy to enhance sustainability and advance the public health agenda will focus on six strategic areas to:

- Impact and contribute to reduction in deaths from chronic kidney disease (CKD);
- Reduce numbers of people entering end stage kidney failure;
- Increase funding for Australian research into kidney disease;
- Increase organ donation;
- Improve access & equity to kidney treatment programs across Australia; and
• Increase the awareness of chronic kidney disease in the Australian community.
Kidney Health Australia’s business strategy recognizes the importance of fostering strategic partnerships in addressing current challenges associated with revenue generation for sustainability, program delivery and research. Key to moving the needle in the public health arena is the reliance on a solid Australian evidence base to underpin policy and program initiatives. The establishment of The Australian Kidney Research Foundation provides a vehicle to advance and promote Australian kidney research while laying a solid foundation for long term sustainable kidney research funding.

Being independent of Government, Kidney Health Australia’s development goals incorporate the management of profitable commercial services designed to underpin the organisation’s infrastructure and operations.

As a result the 2013 business plan for Kidney Health Australia identifies a number of business priorities for 2013, which are aligned to our vision and mission. These are:

1. Early detection and General Practitioner (GP) education;
2. Home based dialysis capacity and support;
3. Living organ donation;
4. Expansion of support and education programs for kidney consumers particularly those in regional, rural and remote areas;
5. Launch the Australian Kidney Research Foundation and engage the kidney sector in reforming funding and support for kidney research;
6. Raise public awareness through advocacy, information and education of the Australian community particularly in regional/rural areas;
7. Implement enhanced sustainable revenue streams through the introduction of a national lottery program and an expanded Red Undies Week program;
8. Launch the Big Red Kidney Bus Project to spearhead early detection and deliver potential supplementary holiday dialysis to rural and remote areas.

I would like to record my thanks to my fellow Directors who have made significant personal commitments themselves in terms of time and effort to support the organisation over the last 12 months.

In addition I would like to record the Board’s appreciation and thanks to the CEO, Anne Wilson, and her team at Kidney Health Australia for their commitment and enthusiasm for the cause throughout what has been a difficult but productive and rewarding year.

Mr Vincent G. Harink
Chairman

Kidney Health Australia
At the commencement of 2012, the task facing Kidney Health Australia involved consolidation and extension of our 2011 financial turnaround. As stated in previous years, Kidney Health Australia’s ability to deliver enhanced services to all our stakeholders is dependent on running our business efficiently, effectively and profitably.

Being independent of government, we rely on the generosity of our donors, the Australian community, our philanthropic and corporate partners, and all those who support our events and community initiatives, as well as profits from our commercial call centre operations in Adelaide.

I am therefore delighted to report that the hard work and commitment of Kidney Health Australia staff, together with the generosity of our donor community, resulted in the organisation posting a profit of $1,373,001. This is a tremendous result made possible through the realisation of donations from our bequest pipeline significantly boosting our Australian Kidney Research Foundation.

As is always the case, 2012 was packed with a range of initiatives and highlights.

Some of these warrant specific mention below:

- Development of the Big Red Kidney Bus project, offering mobile satellite dialysis in conjunction with Southern Health, the Grenda Corporation, Ventura Bus Lines, Latrobe Valley Bus Lines, the Gippsland Mobile Holiday Dialysis Support Group and Perpetual. We are delighted that our first Big Red Kidney Bus will be on the road in 2013.
- Implementation of the first Tiwi Island Health Promotion Program on drinking water for healthy kidneys and a healthy heart funded by the Australian Government.
- Commencement of work in the area of kidney cancer.
- Presentation of the Kincaid-Smith Medal by Her Excellency the Governor-General of Australia Ms Quentin Bryce to Professor David Harris.
• Appointment of a Kidney Health Australia CEO to the Commonwealth Organ and Tissue Authority Advisory Council
• Appointment of new Kidney Health Australia Government Relations Manager
• Completion of the board strategic planning program midyear.

These activities represent just a brief overview of just a few important Kidney Health Australia initiatives for 2012.

In the second half of 2012, a skills audit was undertaken across the organisation with the aim of identifying capability gaps that would need to be addressed in 2013 in order to create a ‘step change’ in awareness and revenue generation going forward. Outcomes of the audit led to a partial restructure of our business to be implemented on 1 January, 2013. This has led to some staffing changes that will better equip our national team to address the funding and programmatic challenges of the future.

At a time when competition for the donated dollar has never been greater, Kidney Health Australia continues to be well supported by the unwavering loyalty of all our supporters who so generously make our work possible. To our financial donors, our lottery supporters, our business customers, our pharmaceutical partners, corporate partners and philanthropic trusts and foundations, our heartfelt thanks on behalf of those whom we serve for supporting our work and organisation.

In 2012, we were once again delighted to have the support of our patrons and ambassadors for a range of activities. The Governor General of Australia, Her Excellency Ms Quentin Bryce – Kidney Health Australia’s Patron-in-Chief kindly officiated at the presentation of the 2012 Kincaid-Smith Medal to Professor David Harris of Westmead Hospital for his services to kidney research. Our patrons Sir Jack and Lady Brabham generously arranged to donate proceeds from a fundraiser in their name to Kidney Health Australia. Throughout the year we were supported by Mr Norman Rowe AM, Mr Tim Mathieson and Mr Tyler Atkins in helping us raise much needed awareness through Red Undies Week launches and our Kidney Kar Rally. We greatly appreciate their ongoing support.

Each year I write that an organisation is only as good as its people and 2012 was no exception. To those staff who left us to pursue other endeavours – many thanks for the contribution you have made to the kidney cause. To the current team who operate very much like our ‘kidney family’ my thanks for your professionalism and dedication. To my Senior Management Team who bring our organisational plans to fruition my personal thanks for your tremendous support and commitment to getting the job done on behalf of our stakeholders.

Finally, I am privileged to be part of a loyal and dedicated board of directors who generously give of their time and expertise. My thanks to Vin Harink our Chairman and to all my fellow directors for the countless hours you so willingly donate to the governance of the organisation and the well being of Australians with kidney disease.

Together we are ‘making a difference’!

Ms Anne Wilson
Managing Director and Chief Executive Officer
Kidney Health Australia
In the past year there has been significant progress in the establishment and recognition of CKD as a major contributor to the overall burden of chronic disease.

The National Health Survey recently reported on the results of its triennial questionnaire which for the first time specifically asked whether the participants had been told they had kidney disease. Given that about ten per cent of adults are known to have CKD (if tested), it was disappointing and revealing to learn that only 0.8 per cent of Australians answered yes to that question. This would appear to indicate that only one in 12 of those with CKD are aware that they have the condition.

Confirmation of the proportion of the population actually having CKD on testing will become available in mid-2013 when the National Health Survey biomarker survey results will be reported. Whatever this new survey shows there is clearly a gap of large proportions between those that may have CKD and those who know they have got it.

Does this matter? All the evidence published in recent years points to the fact that the presence of CKD (even its early stages) is a strong indicator of increased morbidity and mortality. The most recent evidence indicates that the presence of CKD in people with diabetes increases the mortality risk by about 25 per cent above that experienced in people without diabetes – in fact kidney disease can be shown to predominantly account for the increased mortality observed in type 2 diabetes. Many other studies in people with and without diabetes show the same increased risk and that proteinuria (even small amounts called microalbuminuria) accentuates that risk.

**Chronic kidney disease** is a term used widely to describe kidney damage or reduced kidney function (irrespective of the cause) that persists for more than three months. Sometimes CKD leads to kidney failure, which requires dialysis or a kidney transplant to keep you alive.
In the past year there has been significant progress in the establishment and recognition of CKD as a major contributor to the overall burden of chronic disease. The National Health Survey recently reported on the results of its triennial questionnaire which for the first time specifically asked whether the participants had been told they had kidney disease. Given that about ten per cent of adults are known to have CKD (if tested), it was disappointing and revealing to learn that only 0.8 per cent of Australians answered yes to that question. This would appear to indicate that only one in 12 of those with CKD are aware that they have the condition. Confirmation of the proportion of the population actually having CKD on testing will become available in mid-2013 when the National Health Survey biomarker survey results will be reported. Whatever this new survey shows there is clearly a gap of large proportions between those that may have CKD and those who know they have got it.

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Why the gap in identifying the presence of CKD? Firstly CKD usually shows no symptoms so tests are needed for detection. Secondly the proven presence of CKD doesn’t lead to a cure or quick fix leaving some doctors needing to be persuaded to chase it. Usually the diagnosis of CKD means only an intensification of risk reduction measures and a monitoring regimen. We eagerly await the development of a ‘cure’ of underlying kidney disease such as may come with the genetic manipulation of the gene defect in, for example, polycystic kidney disease. Once more specific treatment is available the motivation and justification for early detection programs will increase uptake.

On the positive side several actions are encouraging: the acceptance by the Australian Government of regular kidney function measurements as a requirement for best care of people with diabetes; the likelihood that a collaborative in general practice focussed on CKD will commence this year, the commitment by the National Vascular Disease Prevention Alliance (NVDPA) to an integrated health check new Medical Benefits Schedule item number (that would require kidney testing) and building the evidence base proving the recognised importance of CKD all indicate that CKD is moving to its rightful position as a major player in Australia in contributing to the chronic disease burden.

Survey results suggest only 1 in 12 of those with CKD are aware they have the condition.

A/Prof Timothy Mathew AM
Medical Director
Kidney Health Australia
OUR ORGANISATION
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 delivery of programs in education, advocacy, research and support. Employees across Australia work within four business units comprising Government Relations, supported by a Senior Management Team with responsibility for leadership and the implementation of business strategy.

All business units work interdependently and cross-functionally in order to create more efficient business practices unifying to achieve key business objectives, in accordance with Kidney Health Australia’s mission and vision.
Government Relations
Mr Luke Toy – National Government Relations Manager

With the new Canberra-based National Manager for Government Relations commencing in the fourth quarter of 2012, it has been an exciting time to consider Kidney Health Australia’s renewed government relations, advocacy and policy development push. This year was one of further development, as Kidney Health Australia works to identify a range of key policy issues to pursue with an ultimate goal of developing an updated and comprehensive ‘policy platform’ – which will serve as a touchstone document for the organisation’s submissions, media and advocacy efforts at both a state and federal level.

A key part of this was the development of a Federal Pre-Budget Submission and the ongoing input into a range of formal government consultations. For the Treasurer’s consideration, Kidney Health Australia developed a comprehensive submission covering five key areas ranging from strategic policy, hospital pricing, GP education and support, integrated health checks and live organ donation. Noting the current fiscal climate, all were low cost or no cost and in the longer term many could actually generate significant savings by either improving early detection or getting people off dialysis and back into more regular lives after a successful transplant. In addition to this budget submission, Kidney Health Australia has been quick to advocate with the relevant Government officials on many of these initiatives individually. This also builds upon separate submissions made regarding chronic disease strategies, organ donation, Indigenous health, activity-based funding and kidney cancer.

A key element of Kidney Health Australia’s approach to advocacy lies in the strength we draw from our committed consumers. Through each of our state Consumer Committees, our National Consumer Committee will continue to convey the challenges faced by our consumers and their families and their friends and present these views with suggested solutions and to governments.

Kidney Health Australia continues to advocate on issues of common interest and concern through alliances with the other peak health bodies on the Australian Chronic Disease Prevention Alliance (ACDPA) and the National Vascular Disease Prevention Alliance (NVDPA). This, combined with a concerted effort to increase our media coverage in the mainstream press and as a result, our national profile, means that we are now well-placed to build upon our existing success and advocate more effectively for those with kidney disease in 2013.

Kidney disease contributes to approximately 15 per cent of all hospitalisations in Australia.

The cost of treating end-stage kidney disease from 2009 to 2020 is estimated to be around $12 billion to the Australian Government.
Health

Mrs Anne Revell – National Health Services Manager

Kidney Health Australia’s health team is responsible for the provision of services and programs that support the key areas of education, advocacy and support. In 2012, the health calendar offered a number of highlights including the development of the Kidney Club concept, which has re-energised and rebranded an important patient and family support group model.

Also essential to our support provision, the Kidney Health Information Service continued to provide support, information and referral to nearly 2,000 callers and the well established Henry Giblett Adult Holiday Dialysis Camp in Busselton, WA proved extremely successful again, with a record number of 20 families attending.

Again setting records for participation were our National Kidney Kids Camp and state-based Kidney Kids Capers which have evolved to dynamic and clearly effective programs, building essential peer support and developing self-management skills and self-esteem for children living with kidney disease and their families. This year we have been delighted to now formally welcome back kidney kids who are eighteen or older as volunteers at our programs, creating special mentoring opportunities that benefit all.

A highlight in education has been the development of the new Kidney Kiosk concept which offers touchscreen access to key kidney health information and possibly, an avenue that will improve equity in access to kidney health information nationally.

Also in education, another highlight was the delivery of the Ngawurrayamangamiya Kidney Health Festival on Bathurst Island, Tiwi in conjunction with the staff and local Aboriginal health workers at the Julanimawu Health Centre in the Northern Territory. With week-long activities and a wonderful evening full of music, culture and dance this was a special event, both in its collaborative approach and the longevity of the outcomes of the health messages.
In 2012, we were also very proud to publicly recognise 33 new recipients of our esteemed Operation Angel Awards. These award recipients are all very deserving for many unique reasons. A posthumous award to Vince Tripodi honored his consumer-driven concept of providing mobile holiday dialysis at holiday destinations in Victoria. In 2012 the Big Red Kidney Bus Project was supported by many including the Tripodi family, a small group of Vince’s friends on dialysis at Latrobe Regional Hospital, Monash Health, Fresenius, the Australian Bus Industry Confederation, and trusts and foundations.

**Medical**

**A/Prof Tim Mathew – Medical Director**

2012 has been a most productive year with the Kidney Education for You program successfully completing its next stage of development, Kidney Check Australia Taskforce reaching out to all doctors through its highly acclaimed booklet, Chronic Kidney Disease (CKD) Management in General Practice, a record number of workshops conducted, and with the commencement of the Dialysis Education Project funded by the Australian Government. In addition we have had a large input into KHA-CARI (Caring for Australasians with Renal Impairment) guidelines (now sponsored by Kidney Health Australia) and shared at the Kidney Health Australia-Amgen Leadership Forum aimed at broadening the management skills of senior nephrologists.

**Customer Operations**

**Mr Derek Finch – Head of Customer Operations**

**KHA Comms**

Kidney Health Australia’s telecommunications shop, KHA Comms, provides mobile, home phone and wireless internet service to Australians while supporting Kidney Health Australia through a designated percentage of the bill amount as a tax-deductable donation.

This line of business delivered a significant profit in 2012, consolidating the financial turnaround that started the previous year. KHA Comms continued to bill and maintain Kidney Health Australia’s own telephone services which produced the additional benefit of reduced running costs across the organisation.

KHA Comms holds a strong appeal for people who appreciate that the profit from their bill goes to a good cause, which sets us apart from other telecommunications service providers. Although staffing levels were low throughout the year, recontract rates were maintained at a level above industry standard with over 400 customers re-signing during 2012.

Despite increasing competition within the telecommunications market place, KHA Comms still experienced a small increase in the subscriber base. Our challenge going forward will be to significantly increase customer numbers through a variety of initiatives including expanding our suite of offers, introducing more competitive plans and employing additional staff.
Lotteries

2012 was a year of consolidation for the lotteries team with the impending transition from state-based lotteries to a national lotteries program. The decision was made to conduct the first National Lottery in the last quarter of 2012 with an expected increase in revenue and overall program profitability.

With this planned transition, the 2012 schedule of 12 state lotteries was accelerated to be completed by September to enable the first national lottery to commence. The transition provided certain challenges that included recruitment of suitably skilled staff, the management of the database, overlapping campaigns and maintaining of targets. As a result, valuable information was gained for the planning and execution of the 2013 national program.

Solution K

Solution K is a provider of contact centre services that are utilised by large organisations that choose to outsource and donate proceeds to Kidney Health Australia. Solution K acquired both short term contracts and recurring client campaigns during 2012 with clients continuing to rely on our services for ongoing support with their contact centre needs. Several new initiatives were made and implemented to improve operations, acquisition and ultimately set up this line of business to be able to secure more long term, recurring campaigns.

Sales & Marketing

Mr Frank Daly – Chief Operating Officer

During 2012 the Sales and Marketing Unit was able to deliver support for the kidney community and enhance the public’s knowledge about kidney health through a strong commitment to events and awareness campaigns.

World Kidney Day on March 8 focused on ‘Kidneys for Life – Donate and Receive’ with simultaneous media coverage announcing the nominees of our Operation Angel Awards. At the end of May launches were held across Australia for the campaign, Red Undies Week during Kidney Health Week with the message of ‘It’s time for some decent exposure’ about the health of your kidneys for the second year in a row.

Our events in 2012 contributed to raising much needed funds while driving awareness of kidney disease to our kidney community and the general public. Among the highlights were the Kidney Health Australia Golf Day that was held at Huntingdale Golf Club on March 2; to the Kidney Kar Rally on August 15 through to the 24, travelling from Mandurah, WA to Bendigo, VIC with the Big Red Walk and Big Red BBQs on Father’s Day, September 2.

Repco, City Mazda, Phillip Hoffman Travel, Source Central Partners and our many pharmaceutical partners continued their valuable sponsorship of our work as did a growing group of donors who supported Kidney Health Australia with community fundraising activities.

Marketing also commenced a push into direct mail and social media to help drive awareness of our programs and customer operations services as well as highlight health and lifestyle issues to the growing kidney community.
Corporate Services

Ms Rosanna Caré – Chief Financial Officer/Company Secretary

Kidney Health Australia’s Corporate Services Business Unit is responsible for providing responsive and efficient corporate support. By engaging effectively with Senior Management, Corporate Services adds value by driving the future direction of the Foundation to successfully achieve its targets. The Australian Kidney Foundation t/a Kidney Health Australia “the Foundation”.

Through the collective and collaborative approach of the Senior Management Team and with the support of the Corporate Services Business Unit, Kidney Health Australia was able to maintain its financial stability in 2012. Corporate Services’ contribution via the provision of timely information thus ensured decisions stemmed from a sound basis was paramount in achieving this success. The financial stability of Kidney Health Australia underpins the ability for growth and strategic redirection.

Whilst we have achieved a great outcome over the past two years, there still remains scope to further enhance our processes and procedures, so that we are positioned to grow with the Foundation and provide the support and direction to successfully achieve Kidney Health Australia’s priorities for 2013.
OUR HEALTH AND MEDICAL PROGRAMS
Kidney Health Australia’s health and medical teams are responsible for the provision of services and programs that support the key areas of education, advocacy, research and support.
Medical Programs

Kidney Check Australia Taskforce (KCAT)

Dr Marie Ludlow

The Kidney Check Australia Taskforce (KCAT) Health Professional Education Program was established in 2001 with the aim of improving health outcomes for Australians living with kidney disease through the education of health professionals. KCAT is the leading voice in kidney education in Australia and Kidney Health Australia is the only organisation offering comprehensive education on kidney disease to health professionals.

2012 was another highly productive year for KCAT. Throughout the year KCAT conducted 91 face-to-face education sessions for Australian health professionals. This saw over 2,000 general practitioners, nurses, and other primary care health professionals being educated on the detection and management of kidney disease. In 2012, four new education modules covering cardiovascular risk, conservative care, management of advanced kidney disease, and drug dosing were finalised, to be formally launched in 2013. Constant revision and development of new modules ensures that the educational workshops remain current, with over 80 per cent of participants rating the content as highly relevant to their clinical practice.

In addition to the interactive workshops, KCAT continues to expand into alternative methods of delivery to meet the diverse needs of Australian health professionals. In 2012 KCAT facilitated the development of two new online learning modules, and a webinar series. Available 24 hours a day, every day, these initiatives provide practical access to high quality kidney disease education in a user-friendly way.

2012 also saw the launch of the 2nd edition of our seminal guidelines booklet ‘Chronic Kidney Disease (CKD) Management in General Practice’. This booklet was disseminated to every general practitioner in the country, and due to popular demand is already in its second print run.

Throughout 2012, KCAT continued to build relationships with a variety of stakeholders including Aboriginal health organisations, general practitioner training organisations and independent nurse clinics to implement education sessions and develop new materials. Such initiatives will further help to increase the awareness of kidney disease detection and management, and improve health outcomes.

We would like to thank all the nephrologists and renal nurses who have kindly donated their time and expertise in presenting KCAT workshops in 2012. Volunteer support is critical to the success of KCAT, and we are grateful for the continued endorsement from the nephrology and nursing communities.
Home Dialysis and End-Stage Kidney Disease National Education Projects

Ms Debbie Fortnum

The Home Dialysis Project in 2012 focused on bridging some of the previously identified gaps for consumers.

Funding was sought and approved from the Commonwealth Chronic Disease and Service Improvement Fund which has allowed for the launch of a new three year national education project for those with newly diagnosed end-stage kidney disease (ESKD). The three aims of the project are to firstly improve the health knowledge levels of professionals in the area of home dialysis through online learning packages; secondly, to create a decision aid for patients to choose their best treatment modality and lastly, to fill any current gaps in consumer education tools with new DVD resources and written materials.

Collaboration with many working groups is a critical part of all these projects and many partnerships have been formed. The national network of home these are units and pre-dialysis educators continues to expand and communication is ongoing with monthly newsletters to these groups. The Home Dialysis Project Manager actively participates in four national committees related to home dialysis, The HOME Network and the Home Dialysis Advisory Committee, Queensland Home Dialysis Taskforce and the Victorian Health Networks Home Dialysis Project groups. Presentations have also been given during the year to many workshops and conferences which has assisted in raising the profile of the work of Kidney Health Australia.

The first priority that was identified was education. Therefore, the Home Dialysis website was launched in August 2012 and was received positively by the renal community as a complement to other Kidney Health Australia websites. Found at www.homedialysis.org.au, the website is a comprehensive source of information about all aspects of home dialysis for both consumers and health professionals. The consumer section assists consumers in exploring their options, making their personalised choices and then beginning their journey on home dialysis.

A second person was employed to work on home dialysis projects and is developing the TeleConnect system which connects people living with kidney disease, their carers and family members with people who have similar experiences through phone calls and email support. The relaunch of TeleConnect is expected in 2013.

Life on dialysis requires at least three five-hour treatments each week to filter out toxins in the blood. Both modalities, peritoneal dialysis and haemodialysis can be performed at home, however only thirty per cent of patients dialyse at home, despite more wanting to change to a home therapy. An increase in access to home dialysis can improve the quality of life for those undergoing treatment.
KEY - Kidney Evaluation for You

Ms Theresa Whalen

Throughout 2012 Kidney Health Australia partnered with a range of community organisations, health services and pharmacies in Victoria to provide the KEY to Good Health Program for those at risk of developing CKD. The program was designed to provide a chronic disease risk assessment, including screening for CKD and reviewing risk factors for cardiovascular disease and diabetes. The KEY program also provided opportunities for linking participants into local programs and support. In addition, the program was designed to allow Kidney Health Australia to build and foster relationships across Victoria, as well as increase community awareness, health promotion and early detection of kidney disease.

Each group participated in a lifestyle assessment (some included diabetes and cardiovascular risk) and exit counselling. Some participants were followed up by telephone two months later to ascertain what action they took following the screening to find out if they did visit the GP and were there any changes to clinical management. Three different screening models were utilised and cost-effectiveness was assessed.

Results

A total of 1,314 eligible participants were recruited for KEY between February and October 2012. Of the 1,314 people tested, the most comprehensive KEY (includes risk assessments and urine and blood testing) was conducted in one site, with 121 participants. The second-most comprehensive testing with urine analysis and use of a risk calculator called QKidney occurred in 21 sites, with 969 participants. The QKidney only model was utilised to test 224 people in eight sites. The average age of participants was over 60 years, and previous diagnoses of high cholesterol, diabetes and high blood pressure were common.

The KEY program was effective in detecting markers of and risk factors for CKD. The urine dipstick detected elevated levels of protein in seven per cent of participants and urine ACR (urinary albumin: creatinine ratio) tests were abnormal in 14 per cent. High blood pressure readings were recorded in 56 per cent of participants. Of the participants in the full KEY group 32 per cent had results indicative of CKD stage.
The QKidney risk calculator revealed an average of 20 per cent of KEY participants were at high risk of developing moderate or severe kidney disease in the next five years. The Australian Type 2 Diabetes Risk Assessment Tool indicated that between 67 per cent and 76 per cent of participants were categorised as high risk of developing diabetes in the next five years.

Follow-up telephone calls were successful in establishing contact in 49 per cent of participants. Of KEY participants referred to their doctor, between 76 per cent (full KEY) and 100 per cent (QKidney only) did so.

Despite the different intensities of screening approaches, there were no significant differences between the three groups in the level of engagement with general practitioners following the KEY program, and no significant differences in the extent to which behavioural goals were achieved.

Further funding is required to continue this program. For more information, contact us.

**Acknowledgements**

KEY 2012 was funded by the Percy Baxter Charitable Trust and The John & Thirza Daley Charitable Trust, managed by Perpetual. Funding was also provided by the John T Reid Charitable Trusts, Foster’s Community Grants and the Limb Family Foundation. Special thanks to Flinders University Community Point of Care Services for training and support in point of care testing, including quality management.

**Kidney Cancer Support and Information Service**

**Ms Theresa Whalen**

In Australia (2007) kidney cancer was the eighth most common cancer diagnosed. There were over 2,500 new cases, which is double that of 1982. By 2020 it is estimated that there will be close to 3,000 new cases of kidney cancer diagnosed each year.

Launched in late 2012, the aim of the kidney cancer project is to increase the awareness of kidney cancer in the Australian community, to bring together patients, their families and carers for support and information-sharing and to advocate state and federal governments on behalf of the cancer community. This will be achieved through the development of patient forum on the Kidney Cancer website, creation of a Health Information Service specifically for kidney cancer, providing advocacy for consumers, promotion of the services that Kidney Health Australia provide for consumers and the creation of a kidney cancer patient network.

Initial feedback from the kidney cancer community across Australia has been positive and many are seeking information and support related specifically to kidney cancer.
National Kidney Kids Camp

Offered annually, the National Kidney Kids camp is a five day peer support and respite program for children living with CKD as well as their brothers and sisters. Due to the medical care required by most of these children, it is often the only school-aged camp they are able to experience. Paediatric health professionals from around Australia travel with the children to ensure all medical needs such as dialysis and medication distribution are managed.

During the course of the program children take part in fun, self-esteem building activities which aim to assist them in creating supportive relationships with others who are living with a similar condition. Camps also provide parents and carers with much needed respite.

The 14th National Kidney Kids Camp was run from the 10-14 April and included a record number of 57 children, 41 volunteers, 15 health professionals and six Kidney Health Australia staff. Themed ‘Cirque du Kidney’ the program took place at Camp Manyung in Victoria and in keeping with the theme, on arrival children were split into camp groups of acrobats, jugglers, lion tamers and clowns. Activities on camp included flying fox, archery, giant swing, high ropes, a camp concert as well as the hotly-contested camp karaoke night. Children also enjoyed an excursion day to laser tag and the amazing Silver’s Circus.
At camp this year, four volunteers were ex-kidney kids, now aged 18 and over who participated as role models and mentors for the kids. This is an initiative that Kidney Health Australia will grow and improve in coming years.

This was also the first year that Kidney Health Australia established an across the board reimbursement system for health professionals attending camp, as well as incorporating professional development sessions for the nurses in attendance. The National Kidney Kids Camp was kindly supported by the Honda Foundation and the James N. Kirby Foundation.

National Kidney Kids Camp
A record 186 children from around Australia took part in our five Kidney Kids Capers programs throughout 2012. These programs, developed to deliver peer support and respite for children living with CKD and their families are provided free of charge and are made possible with the assistance of an enthusiastic team of volunteer carers in each state.

A special thanks to the Marian and E.H Flack Trust and Morialta Trust Incorporated for their contributions and Lotterywest who made the Western Australian program possible.
Kidney Club

In early 2012, Kidney Health Australia reviewed the existing patient support program model. Identifying that opportunities existed in changing the sometimes negative perceptions patients and their families could have of attending ‘support’ group meetings, the existing model was adapted to ensure the effectiveness of outcomes. As a result the improved concept of ‘Kidney Club’ was launched in Adelaide in 2012, with the model providing a friendly environment where patients, carers and family members could talk openly about their personal experiences and ask questions from others. Meeting agendas are patient-driven, and now focus on providing peer support and education to clearly enable people to become better self-managers of their health.

The Adelaide Kidney Club group held four meetings through 2012 with well-received presentations from a renal nurse, transplant coordinator, leading renal dietician and an overview of holiday dialysis opportunities. Kidney Club has now expanded into Toowoomba in regional Queensland, Canberra and Alice Springs, where one attendee drove 500km each way from Tennant Creek to attend. All Kidney Club meetings were well-attended, and resulted in positive social and educational outcomes with a total of 178 people attending the meetings.

Kidney Health Information Service

The Kidney Health Information Service provides information, education, referral and support via the free call number (1800 454 363), email, direct local phone calls and social media. The service continues to be utilised by consumers, carers, health professionals, members of the general public and those with a particular interest in kidney disease.

In 2012, Kidney Health Australia expanded the dedicated staff supporting this service fielding nearly 2,000 enquiries and providing over 50,000 pieces of educational material (brochures, pamphlets, booklets, posters etc.) to enquirers across the country.

The most frequent enquiries have been on recent diagnosis and understanding terminology, available management options, transplantation, nutrition and travel support. Enquiries regarding kidney cancer have also continued to grow. A special thanks to Australian Executor Trustees, State Trustees Australia Foundation-Lorna Muriel Jenkins and The Fay Fuller Foundation for their support.
**Kidney Community**

2012 saw the evolution of the Kidney Community newsletter. This monthly, colour newsletter continued to provide regular communication to anyone with an interest in or affected by kidney disease. With sections including consumer articles, updates on Kidney Health Australia events and activities, CKD and diabetes-friendly recipes, medical information updates and details on new initiatives for patients and families, these newsletters have been expanded to four pages and continue to be very well-received.

The decision to ensure that the newsletters would be posted to people without internet access continues and nearly 2,000 people were registered for the monthly update by the end of the year.

**Henry Giblett Adult Holiday Program**

Held from 11-17 November, the popular annual Adult Holiday Program in Busselton was attended by a record 20 Western Australian families who travelled from as far away as Geraldton. Through the generous support of Lotterywest, and the management and staff of Fresenius Medical Care and other dedicated sponsors including Diaverum, Baxter, Gambro, Busselton Hospital, St John Ambulance and Grand Mercure Busselton, families enjoyed a break from their normal routine and took in the sights and activities of this beautiful coastal food and wine region.
The key to the program’s success, a temporary mobile dialysis unit, was again set up in the Busselton St John Ambulance Sub-Centre, near the accommodation so that consumers could receive their dialysis treatment while on holiday. For many of the people attending, this was the first holiday opportunity for many years and participants were overwhelmed with appreciation for this program.

One Deadly Step
Kidney Health Australia was delighted to support the One Deadly Step program within New South Wales. This program, run by the Chronic Care for Aboriginal People Unit in the NSW Ministry of Health, screens for indicators of chronic disease amongst Aboriginal and Torres Strait Islander peoples at dedicated community family events - which have gathered support from the National Rugby League. In 2012 the program has run at Kempsey, Dubbo, Griffith and Redfern screening more than 800 people.

Kidney Health Australia has contributed to this program providing clinical guidance and consultation, the facilitation of the provision of point-of-care testing machines, training in their use and dedicated staff to assist in the screening and education at the events.

Operation Angel
Recognising outstanding people who have made exceptional contributions to the kidney community, the Operation Angel Awards have been presented over many years to kidney patients, carers, family members, volunteers and health professionals. Acknowledging the esteem in which Operation Angel Awards are held, a working group was established to reinvigorate the program for 2012.

Nominations were received from across Australia with ceremonies held during Kidney Health Week in May to recognise and honour the 33 Operation Angel Award recipients for 2012. A special thanks to KPMG for funding the South Australian and Victorian Operation Angel ceremonies.

Family Accommodation Initiative Transplant Housing (F.A.I.T.H.)
Over 2012, 12 separate families benefited from the two FAITH houses established in Western Australia. These families included live kidney donors and their recipients, a paired kidney exchange program donor and recipient and a home dialysis training patient. Families from rural areas came from all over the state including Bunbury, Port Hedland, Geraldton, Kalgoorlie, Jurien Bay, Stratham, Exmouth and Northampton.

Clarkey’s Kidneys team were one of the highest fundraisers nationally.
Big Red Kidney Bus

Kidney Health Australia raised $170,000 from trusts and foundations to progress the Big Red Kidney Bus Project in 2012 and the dedicated group of people on dialysis at the Latrobe Regional Hospital Dialysis Unit, who initiated this project, separately raised $50,000 through their own fundraising activities. The Big Red Kidney Bus Project will provide people on dialysis the ability to break the regimented routine of dialysis at home or hospital and take a family holiday, which many are currently unable to do.

Discussions with Monash Health are progressing for their management of all medical and clinical aspects of this project. Following the official handover of the keys of the donated bus to Kidney Health Australia by supporters Ventura Bus Lines, the expectation is that all modifications and renovations will be completed and the bus launched in 2013.

This project is being generously supported by H & L Hecht Trust, managed by Perpetual, The Jenour Foundation, The Pierce Armstrong Foundation, The L.R Cazaly Trust Fund The Grenda Foundation, Ventura Bus Lines and Latrobe Valley Bus Lines.

Big Red Walk

1,300 walkers across the country took part in the first national Big Red Walk campaign held on Father’s Day. The Big Red Walk raised awareness of kidney disease in the general public through media, while raising over $65,000 in funds for the Big Red Kidney Bus initiative. With a variety of walks offered, all were able to participate regardless of their physical ability and all walks concluded with a healthy barbeque. With the enthusiasm of the commencement of this campaign, the event will be repeated in 2013.
Community Education and Awareness

Consumer education and community awareness continued to be a major focus with events, displays and activities held nationally over the year ensuring direct exposure of key health messaging to over 9,000 people.

Some key highlights:

Kidney Consumer Education Forums

On 17 November, more than 50 people attended the Launceston consumer education forum which targeted participants with both chronic and end-stage kidney disease. Titled ‘Keeping Informed About Our Kidneys’, sessions included presentations by Tasmanian Heartmoves, renal dietitian Lisa Clark and nephrologist and Medical Director A/Prof Tim Mathew. Key presentations were delivered throughout the forum by members of the Tasmanian Consumer Committee who spoke on their experiences living with dialysis and a kidney transplant.

In Western Australia, the partnership with major Perth hospitals, Sir Charles Gairdner, Royal Perth and Fremantle continued in order to deliver the WA Renal Education Seminars. Two levels of free education seminars were delivered throughout the year to cover the needs for early and end-stage CKD. These seminars support self-management with presentations including demonstrations and patient perspectives.

General Public Community Education Forums

Kidney Health Australia delivered community education forums themed ‘Linking Kidney Health, Heart Health, Blood Pressure and Diabetes’ in Mildura, Bendigo, North Sunshine and Werribee throughout the year. These day-long forums attracted a total of 600 members of the general public and were supported by local screening activities to identify increased risk of kidney disease by trained health staff. Invited speakers for the programs included nephrologists, cardiologists, a cardiac rehabilitation nurse, renal nurses, diabetes educators, nutritionists, an optometrist and a podiatrist. Evaluations consistently showed increased knowledge on kidney health after every forum. Our generous supporters of the
OUR HEALTH AND MEDICAL PROGRAMS

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**Indigenous Health Education**

Kidney Health Australia was delighted to be invited to work with local Aboriginal Health Workers at the Julanimawu Health Centre on the Tiwi Islands in the Northern Territory to deliver the Ngawurrayamangamiya (Take Care of Yourself) Kidney Health Festival. A key part of the activities in the lead up to the festival was the program run in the local school with the message ‘Drink Water for Healthy Kidneys and Healthy Heart’. This program ran activities with the students to understand some of the concepts of what your kidneys do, and introduced the character Billy the Kidney, who with the assistance of Muso Magic and Red Dust Role Models, developed a song and dance with the children about why it was important to drink water for healthy kidneys and healthy heart.

Dr Greg Perry, Director of Renal Services NT and local speakers shared stories about kidney disease and kidney donation to a community gathering of 200. Following enthusiastic performances by the local children of their ‘Billy the Kidney’ song and dance and beautiful music from the local Strong Women’s Choir, a freshly prepared healthy meal was served to all attending. Kidney Health Australia gratefully acknowledges the financial support of the Australian Government to make the festival possible.

The incidence of kidney failure is considerably greater in Indigenous people compared with non-Indigenous people.
Kidney Health Australia worked in community partnership again with the Aboriginal Health Council of South Australia as invited educators in the Aboriginal Health Worker Certificate 3 and 4 training program. This training also extended to one full day focusing on CKD in Port Augusta.

Kidney Health Australia was also invited to participate in community partnership at the Aboriginal Health Festival in Mildura, Victoria providing an excellent opportunity to evaluate newly developed educational material and identify opportunities to further enhance existing resources.

**Kidney Kiosk**

Kidney Kiosk was developed in 2012 as an integrated educational touch screen unit to ensure important health information was available to people living with kidney disease and their families living in regional or remote areas or to those who don’t have access to the internet.

Kidney Kiosk is a portable, easy-to-navigate touch screen that can be used while patients dialyse or be placed in waiting rooms enabling people to have access to up-to-date information on nutrition, Indigenous health and further resources for self-management with a simple touch of the screen. Each of the nutritional presentations is delivered by an online presenter, who clearly explains the concepts in easy-to-understand terms.

This initiative was funded by the Queensland Government and is being piloted at Cairns Base Hospital and the Townsville Hospital.

**Translation Project**

Funds were received through trusts and foundations to commence the translation of key kidney health information. Initiated at the suggestion of St Vincent’s Hospital and Western Health, the initial stage of the project saw the translation of the pivotal ‘Are you at risk?’ A4 poster.

This health information sheet concisely outlines kidney disease, the risk factors, key details to emphasise the importance and ease of early detection and a snapshot of the severe consequences of progression. With the funding available, this information has now been
translated into nineteen community languages that have been identified with the assistance of health professionals nationally as initially being of the most value.

Following the initiative for risk information sheets, Kidney Health Australia’s kidney health fact sheets were also translated into Chinese, Greek, Italian, Vietnamese and Arabic.

Our kind supporters included the Joe White Bequest, The Isabel and John Gilbertson Charitable Trust, the Steadfast Foundation and The Brook Foundation care of Public Trustee for the ACT.

Kidney Awareness Charity Bike Ride
The 7th annual ride, organised by the Harley Owners Group Tasmania chapter, saw more than 80 riders from around the state take part earlier this month. Riders departed from the Prospect Richardson’s Harley Davidson store and met at the Ross Oval for a barbecue. Patients and carers and members from the Tasmania Consumer Committee were able to attend, undertaking blood pressure checks and discussing the importance of looking after your kidneys.

Kilometres for Kidneys
Kidney Health Australia launched the first Kilometres for Kidneys event in Sydney as a lead up to The Big Red Walk with great success. Members of the public were invited to exercise on a range of donated equipment in a mission to promote having a healthy lifestyle and the importance of regular exercise. With Martin Place transformed into the kidney health gym we were delighted with the response from the public with over 100 people donating ten minutes of their day to keep the machines continuously running. With help from volunteers from local NSW universities, members of the public were educated about kidney disease and its risk factors and the importance of communicating your wishes about organ donation. Kidney Health Australia hopes to expand this event into the future.
CONSUMER PARTICIPATION
Consumers working together across states and territories can provide an important role in working to highlight and resolve issues experienced by Australians living with kidney disease.
National Consumer Council

The National Consumer Council consists of a chairperson from each of the state and territory consumer committees. Consumer committee members bring a wealth of experience to bear, including personal experience with CKD and dialysis, through to the experience of having had a kidney transplant, having been a carer, a nurse or in some cases, a kidney specialist.

The National Consumer Council continues to advocate for the key points identified in the position statement released in 2010: ‘The impact of kidney disease and what government should be doing about it’. The statement provided an insight into patients’ views of how their families, carers and they themselves are treated by the current system and the areas needing urgent reform.

This position statement identified the following four interventions needed for kidney patients:

- adequate dialysis capacity that enables patients to:
  - access and choose from a full range of treatment options in their own region
  - access respite and holiday dialysis in other regions and interstate to facilitate contact with family and friends
- a patient transport and accommodation scheme to ensure patients who need to recurrently travel to receive dialysis treatment are adequately reimbursed
- a scheme that meets out-of-pocket expenses incurred by patients choosing to undertake dialysis treatments in their own homes
- a reimbursement scheme for out of pocket medical costs for people donating a kidney to a loved one
The National Consumer Council met three times in 2012, with discussions focusing on adequate electricity subsidies for home dialysis patients, organ donation rates and reimbursement for out-of-pocket expenses for living kidney donors, as well as payments for carers.

The National Consumer Council was also delighted to maintain an Indigenous consumer representative, so all activities of the committee appropriately considered this significant kidney consumer group.

**State and Territory Consumer Committees**

Kidney Health Australia’s state and territory consumer committees have continued to advocate on key issues affecting people living with kidney disease, such as the impact of rising electricity prices on people who undertake home dialysis; issues affecting carers and the need to create visibility and ultimately action in response to the potential closure of a dialysis satellite unit.

State consumer committees have also been extremely proactive in community awareness throughout the year, with members delivering community education presentations and assisting with awareness events. A key project for several of the committees was participating in the delivery of the Big Red Walks in their states, with members taking an active role in contributing to the success of the events and also generously promoting and supporting the fundraising aspect of the event.

Members of the state and territory consumer committees have also been invaluable in assisting as consumer representatives on various external health committees and also in providing guidance on a range of papers, publications and organisational promotional material.
OUR RESEARCH
Kidney Health Australia is one of the main non-government supporters of kidney research in Australia.
Kidney Health Australia’s continued commitment to supporting research is evident from our extensive grants and scholarship program. We appreciate donations to, and sponsorship of, our research program, as this enables us to increase the levels of funding available to support valued research in the area of kidney and urinary tract disease.

The relative level of support flowing to kidney research in Australia has never matched the expenditure on kidney disease and kidney failure. This continues to be true with the NHMRC allocating about one per cent of its funds to the kidney area when we spend about two per cent of the total health budget. Kidney Health Australia is one of the main non-government supporters of kidney research in Australia and recently redirected its program towards the public health arena. The recently completed Australian government-sponsored ‘Strategic Review of Health and Medical Research’ stresses the need for support of the research workforce over the long term – a major finding from our own survey of researchers in the kidney sector conducted in 2012.

Recent advances in the clinical arena are exciting 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) and significant advances have been made in understanding the processes and in being able to reduce the damage and scarring that causes progression of most kidney disease. These advances will 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. For this reason Kidney Health Australia is establishing a Research Foundation with the task of significantly increasing the funds available for Australian kidney research.

Grants and scholarships awarded for 2012

A total of sixty-one applications were received by Kidney Health Australia for funding support in the calendar year 2012. Our Medical and Scientific Advisory Committee awarded sixteen separate grants and scholarships to the value of $476,749 into kidney-related research projects in university departments, medical research institutes and hospitals throughout Australia. Support to investigator-driven research totalled $371,749, plus an additional $75,000 funding for strategic targeted research.

The Nursing Grant program aims to support renal nurses pursuing a Masters Degree and encourage nurses to pursue a career in renal nursing, in any of its components - clinical practice, education or research - across the continuum of CKD, from prevention to early detection to renal replacement.

Biomedical Scholarships

The new direction of Kidney Health Australia research funding aimed at a public health agenda included the withdrawal of new scholarship offers. The nephrologists are in general well-supported in post-graduate study by funds specifically targeted at medical graduates and scientists have access to a variety of sources for PhD support.

In 2012, one biomedical scholarship was awarded continued funding and two were newly awarded scholarships. Funding allocated was valued at $105,000.

We actively encourage students receiving Kidney Health Australia funding to apply for NHMRC scholarships each year, to make the most of our research dollar.

Sponsored Scholarships

Kidney Health Australia encourages groups and individuals to consider supporting research in this manner. Funding biomedical scholarships is a most valued and meaningful way to ultimately promote better health outcomes in kidney patients. We are always interested in hearing from individuals wishing to donate funds for scholarships or grants. All offers are valued and presented to the Medical and Scientific Advisory Committee for consideration.

Continuing PhD scholars for 2012

Dr Scott Wilson
Supervised by Prof Stephen Harrap (Medical)
Department of Physiology, University of Melbourne VIC

Understanding changes in blood pressure in dialysis patients with chronic renal failure – a comprehensive clinical and genetic analysis
Project Grants

Project grants worth $50,000 each for use over one to two years were a new addition to the Kidney Health Australia program. The competition was strong and most applications were considered suitable for support should more funds be available.

Dr Rachael Morton et al
School of Public Health, Sydney Medical School – University of Sydney NSW

Patient Information about Options for Treatment (PINOT) follow-up study

In 2009, a national study of treatment options for patients with stage 5 chronic kidney disease (PINOT) found 60 per cent of new patients started on in-centre haemodialysis despite plans for home based dialysis. The above-mentioned study also found that 14 per cent of patients planned to forgo dialysis in preference for conservative treatment. The aims of the PINOT 5-year follow-up study are to firstly determine what proportion of patients who planned for home haemodialysis or peritoneal dialysis, actually made the transition to home dialysis; and secondly to determine what proportion of patients who planned for conservative care, actually started dialysis, or underwent a time-limited trial of dialysis within three and five years. Methods: Renal clinicians from the 66 participating renal Units will complete a brief survey detailing each of the original incident patient’s current and past dialysis treatments and mortality status. Data will be collected at the three and five year follow-up time period (i.e. September 2012 and 2014). Significance: The results from this study will enable more accurate estimates of dialysis resources use in economic modelling of stage 5 CKD and inform policy for the transition to home dialysis, as well as policy to provide appropriate palliative resources for end-of-life-care.

Dr Lynelle Moon et al
Health Group, Australian Institute of Health and Welfare (AIHW) ACT

Agreement of hospital admitted patient diagnoses with cause of death diagnoses for patients with end-stage kidney disease

To use linked hospital diagnosis and mortality cause of death data from New South Wales and Western Australia to assess the likelihood of a patient who has been hospitalised with a diagnosis of end-stage kidney disease (ESKD), and who subsequently dies, having ESKD listed as a cause of death on their death certificate.

Dr Martin Gallagher et al
Renal and Metabolic Division, The George Institute for Global Health NSW

Outcomes and burden of renal disease in NSW

The number of Australians with chronic kidney disease (CKD) and End Stage Kidney Disease (ESKD) continues to rise inexorably. As distance from nephrology services increases there is evidence that outcomes are worse from CKD patients, with variable effects upon outcomes for ESKD patients. There have been no studies looking at the comparison of the burden of CKD and ESKD between rural and urban NSW. We aim to compare the disease burden, access to care and health outcomes of CKD and ESKD in rural versus urban NSW.
Dr Germaine Wong et al  
Centre for Kidney Research, Kids Research Institute, the Children’s Hospital at Westmead NSW  
*Wealth and health in kids with CKD*

The inverse relationship between socio-economic status and chronic illness is well established in the adult population. The link between wealth, social inequality and the health of children and adolescents with chronic kidney disease is unknown. This proposed program of work will examine the novel relationship between macro economic measures such as total annual income and income inequality, and the health outcomes of school aged children with chronic kidney disease.

A/Prof Nicole Isbel et al  
University of Queensland QLD  
*A study investigating relationship between bone and vascular health in patients with Chronic Kidney Disease*

Patients with chronic kidney disease (CKD) have a higher risk of cardiovascular disease (CVD). Treatments already in use for CVD may not work as well in CKD patients because of the complex problems these patients suffer such as blood vessel stiffness and calcification. There is evidence of an important link between changes in bone density and CVD in these patients, but a better understanding of how and why these changes occur is needed. We will look at whether a new scan technology using low radiation exposure can detect early changes in the bones of CKD patients that predict their risk of CVD. By detecting these changes earlier, better treatment can be offered to CKD patients for both loss of bone density and heart disease.
Grants for Nurses Pursuing Masters Degree

Kidney Health Australia provides grants for registered nurses wishing to study for a Masters Degree in Nursing or Public Health. The aim of the program is to encourage nurses to pursue a career in renal nursing in any of its components - clinical practice, education or research - across the continuum of CKD from prevention, early detection to renal replacement.

Seven nursing grants were awarded, the scholarships are valued at $3,000 each, for a maximum of three years – total of $21,000 for calendar year 2012.

Ms Jacqueline Moustakas
Master of Nursing (Research)
Flinders University, SA

Ms Marie Mcintosh
Master of Nursing (Nurse Practitioner)
University of Newcastle, NSW

Ms Jane Van der Jeugd
Master of Nursing (Nurse Practitioner)
Flinders University, SA

Mrs Wendi Bradshaw
Master in Nursing Practice
Deakin University, VIC

Ms Toni East
Master of Nursing - (Nurse Practitioner)
Flinders University, SA

Mr Anthony Perkins
Master of Nursing - (Advanced Practitioner)
University of Newcastle, NSW

Ms Lisa Shelverton
Master of Advanced Clinical Practice
Flinders University, SA

Summer Vacation Scholarships

These scholarships are valued at $3,000 and designed to provide assistance to undergraduates undertaking summer vacation research in the area of kidney and urinary tract. One of the three applicants were awarded funding for 2012.

Miss Electra Tomasino
Supervised by Dr Aaron Petersen
School of Sport & Exercise Science, Victoria University, VIC

Strength training benefits for wellbeing of kidney failure patients

Targeted or Strategic Research

In 2012, an amount of $75,000 was awarded by the MSAC to targeted areas deserving support and assisting Kidney Health Australia in its mission to free Australia of kidney disease. The sole recipient was:

ANZDATA Registry

The internationally acclaimed ANZDATA Registry has been funded substantially by Kidney Health Australia since its formation. It is one of the major accomplishments of the Australian and New Zealand nephrology community and has contributed importantly to knowledge, planning and best practice in clinical care over many years. For calendar year 2012, MSAC awarded ANZDATA Registry $75,000 towards its general operating costs. Learn more at www.anzdata.org.au.
Awards in excellence in research

Clinical Nephrology Presentation – ANZSN Scientific Meeting

Special awards given this term by Kidney Health Australia for excellence in medical research included an annual prize valued at $5,000 for the best Clinical Nephrology Presentation at the annual Australia and New Zealand Society of Nephrology (ANZSN) Scientific Meeting. This award is judged on abstract and presentation with all presenting members of the ANZSN eligible.

Winner of the Clinical Nephrology Presentation for 2012 was A/Prof John Collins, University of Auckland, NZ

Clinical and Laboratory Research Presentations – TSANZ Scientific Meeting

Kidney Health Australia has sponsored two annual awards at the Transplantation Society of Australia and New Zealand (TSANZ) each to the value of $1,000 for the best clinical and laboratory based presentations judged on abstract and presentation.

The 2012 winner(s) of the Clinical and Laboratory Research Presentations – TSANZ Scientific Meeting

Winners for 2012 were:

Clinical Research Presentation 2012
Dr Suda Swaminathan, Royal Perth Hospital, WA

Laboratory Research Presentation 2012
Dr Robyn Sutherland, Walter & Eliza Hall Institute of Medical Research, VIC
Kidney Health Australia Kincaid-Smith Medal

This prestigious award, given only periodically, is the highest scientific accolade of Kidney Health Australia. It is awarded on the recommendation of Medical and Scientific Advisory Committee for outstanding contributions to the cause of nephrology.

This year’s honouree was Professor David Harris awarded by Kidney Health Australia’s Patron-in-Chief, The Governor-General Ms Quentin Bryce AC CVO. Professor Harris made major clinical contributions in the prevention and management of CKD end-stage kidney disease by dialysis.

His laboratory interests are focused on determining the mechanisms of damage in the kidney that lead to kidney failure. Professor Harris’ group is also investigating novel therapies, including DNA vaccination and modification of immune mechanisms that may lead to a slowing of progressive kidney disease.

Past winners include:
2010 Professor Judith A Whitworth AC
2005 Professor Stephen Holdsworth
2002 Professor Anthony d’Apice
2000 ANZDATA Registry
1996 Professor Villis Marshall
1994 Professor Robert Atkins

Kidney Health Australia’s continued commitment to supporting research is evident from our extensive grants and scholarship program. We appreciate donations to, and sponsorship of, our research program as they enable us to increase the levels of funding available to support valued research in the area of kidney and urinary tract disease. Should you wish to donate funds for a grant or scholarship, supporting research in the area of kidney and urinary tract health, we would like to hear from you.
KHA-CARI  Caring for Australians with Renal Impairment Guidelines

Caring for Australians with Renal Impairment (CARI) is a national evidence-based project that started in 1999 with funding from the pharmaceutical industry. The idea for such a project came from a dialysis, nephrology and transplant (DNT) sub-committee meeting towards the end of 1998, and work began in earnest in early 1999. The first set of Clinical Practice Guidelines appeared in March 2000. The two bodies responsible for the CARI Guidelines are the ANZSN and Kidney Health Australia. At the beginning of 2011 a contract was struck between CARI and Kidney Health Australia that saw Kidney Health Australia guarantee the funding of CARI for a three year period in return for a renaming of the CARI process KHA-CARI and an opportunity for Kidney Health Australia to review the work-plan on a regular basis.

As an indication of the current work-plan the following indicates the activity of the KHA-CARI process:

**New Guidelines**
- Cardiovascular Disease
- Recipient Assessment for Transplantation Diagnosis and Treatment of Urinary Tract Infection in Children
- Early Chronic Kidney Disease

**Updated Guidelines**
- Dialysis Adequacy (HD)
- Peritonitis Treatment and Prophylaxis
- Vascular Access
- Iron

**Adaptation of KDIGO Guideline**
- Acute Kidney Injury

**Commentary on KDIGO Guideline**
- Glomerulonephritis
- Anemia in CKD
- BP Management in CKD
- Lipid Management in CKD (KDIGO guideline not yet published)

The current agreement between CARI and Kidney Health Australia is due to expire at the end of 2013 and consideration of a new agreement has begun. Australia is continuing to work collaboratively with other countries in the guideline area. The CARI office is at Westmead Children’s Hospital and the CARI project has enjoyed strong and continuing support in 2012 from Amgen, Baxter, Novartis, Roche, Servier and Shire.
OUR MARKETING + FUNDRAISING
Further development of all marketing areas continued in the Sales and Marketing Unit during the year. There was continued success in the appeal campaigns, strengthening corporate partnerships and signature events, and development in bequests and philanthropic trusts.
Communications

World Kidney Day’s theme on March 8 focused on organ donation with the tagline ‘Kidneys for Life – Donate and Receive’. The success of the day however came from local media coverage after the announcement of Operation Angel Award nominees.

Kidney Health Week at the end of May was branded for the second year in a row as Red Undies Week and saw a great deal of media coverage. The program was designed to communicate with a younger audience with a cheeky campaign theme in order to expose the fact that 1.7 million Australians are unaware they have CKD and encourage self risk assessments at www.checkmykidneys.com.au

Awareness around Red Undies Week was raised by television and radio community service announcements presented by Kidney Health Australia Ambassador Mr Tim Mathieson and through five state launches during the week. The launches engaged celebrities and
consumers to show the importance of pharmacy in the early detection of kidney disease and ran alongside a social media campaign.

Many news stories were highlighting that many Australians who live with undiagnosed kidney disease are up to a 20 times greater risk of heart attack or stroke. The awareness week generated 115 broadcast and print clippings.

Kidney Health Australia is continually growing an engaged kidney community through tools like the monthly Kidney Community newsletter and Facebook.
Direct Mail Appeals
Thanks to the loyalty of our supporters, results from our four successful appeals in autumn, winter (tax), spring and summer (Christmas) were excellent. The tax appeal was our most successful ever. Titled ‘Louie’s Goals’, the story attracted strong response from readers and generated a great deal of interest.

Bequests
Regardless of the amount, a bequest to Kidney Health Australia can help in many ways. Funds received in 2012 from generous benefactors have enabled us to continue our important work and positively impact those living with kidney disease. We are genuinely grateful for their generosity and support.

For further information regarding our appeals and bequest programs, call 1800 454 363.

Community Fundraising
At Kidney Health Australia we are invigorated by the support of our community fundraisers who work hard for us to make a difference.

Kidney Health Australia is appreciative of the support we receive from many who raise funds and awareness on our behalf.

We had slimming challenges, swimming challenges, walks and fun runs where fundraisers initiated their own event. Not only is it satisfying to complete a challenge but the friendships that are built can be life-changing.

Live kidney donors Kath Barun and Daniel Bell who ran the Puffing Billy fundraiser run for Kidney Health Australia.
Our special thanks to:

Ride to Give – Paris to Barcelona Bike ride
Greg Frankish – Golf Day on the Gold Coast, Queensland
Almighty Industries – Orange fundraising @ Regatta
Tony Crescitelli - Dinner Dance in Adelaide, South Australia
Central Coast Support Group
Brodie Hunter – Golf Day in Ararat, Victoria

There are many others who have made outstanding contributions as individuals, groups and clubs. They have worked extremely hard and we appreciate every dollar contributed to Kidney Health Australia.

If you are interested in fundraising for Kidney Health Australia, please ring our freecall number located at the back of this report.

Funds received in 2012 from generous benefactors have enabled us to continue our important work.

Dialysis patient Steven Cartin raises funds monthly during his ‘Rides for Dialysis’ around Geelong, VIC
Events
The Kidney Kar Rally program is Kidney Health Australia’s longest running event and is a vital component to Kidney Health Australia’s fundraising activities, while providing an unforgettable experience for the close-knit group of rallygoers.

In its 24th year, the Kidney Kar Rally raised $501,720 gross. The route was extensive with a ten day rally covering over 4,500 kilometres starting in Mandurah, Western Australia, travelling to Bendigo, Victoria via the Nullabor Plain. The Kruise and Shine for all classic and vintage cars ran for a second year, driving along a slightly different route and raised a total of $27,728 gross in 2012.

Highest Fundraisers:
1st: Kar 8 – Bathurst Surf Lifesaving Club – Peter Ward, Graham Ward, Richie Farrar
2nd: Kar 940 – Australiana – Robert Rowlands, Alexander Daffy
3rd: Kar 68 – Artline Rally Team – Mike Kluver, Mark Poli

Outright Winners:
1st: Kar 68 – Artline Team – Mike Kluver and Mark Poli
2nd: Kar 508 – Amy’s Team – Robert Cameron and Dean Mosdall
3rd: Kar 41 – 2 Jewels in the Crown - Khaled El Sayed and Justin Moloney
**Kidney Health Australia Golf Day**

Kidney Health Australia held its 9th annual Golf Day at Huntingdale Golf Club in Melbourne with Subaru Melbourne as the major sponsor. Participants enjoyed an amazing day of 18 holes of golf, lunch, dinner and entertainment by the operatic and engaging Three Waiters performers at night. The event raised over $48,480 gross.

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