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

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

- 11,446 were receiving dialysis treatment at the end of 2012.*
- 845 kidney transplant operations were performed in Australia in 2012.*
- At the end of December 2013 1,076 people were waiting for a kidney transplant in Australia.

* latest statistics available
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As the national peak body, Kidney Health Australia works to raise awareness of the need for prevention, early detection and improved treatment options for kidney disease, as well as the need for increased organ donation rates, both amongst members of the general public and amongst medical professionals.

In 2013 Kidney Health Australia celebrated its 45th Anniversary – a landmark year for the organisation. As outlined in the Chief Executive Officer’s report, it is with pride that we look back over our 45 year history, and see everything the organisation has achieved in that time.

Certainly, as Chairman of Kidney Health Australia, I am very proud to have seen the organisation grow as the national peak body serving Australia’s kidney community, particularly making such a significant contribution to the funding of vital kidney research as well as development and implementation of a range of national programs and services.

The past year saw the continuation of a tough external environment, which presented challenges for Kidney Health Australia to overcome, with regards to fundraising and garnering support. The organisation continues to be committed to improving the lives of those affected by kidney disease and, as we look to the road ahead, 2014 is already shaping up to be an exciting time for the organisation.

Our business strategy is built around providing support to Australians affected by kidney disease, including families and carers, whilst also ensuring a public focus on early detection and prevention through our four guiding pillars of education, advocacy, research and support.

Kidney Health Australia continues to be independent of Government which means our development and sustainability goals incorporate the management of profitable commercial operations designed to underpin the organisation’s infrastructure and operations.
The past year saw the continuation of a tough external environment, which presented challenges for Kidney Health Australia to overcome, with regards to fundraising and garnering support.

Our strategic goals listed below underpin Kidney Health Australia’s 2014 business priorities, all of which are aligned to our vision and mission. We aim to:

1. Impact and contribute to reduction in deaths from chronic disease
2. Reduce numbers of people entering end stage kidney failure
3. Increase funding for Australian research into kidney disease
4. Contribute to an increase in Australia’s organ donation rate
5. Improve access and equity to kidney treatment programs across Australia
6. Increase the awareness of CKD in the Australian community

I would like to formally extend my thanks to my fellow Directors, who continue to dedicate themselves to the organisation, and whose strategic counsel is a key factor in Kidney Health Australia’s growth and success.

In addition, I would like to record the Board’s appreciation and thanks to the CEO and Managing Director, Anne Wilson, and her team at Kidney Health Australia for their unwavering commitment and enthusiasm for the cause, and their dedication to helping the organisation continue to grow from strength to strength.

Mr Vincent G. Harink  
Chairman  
Kidney Health Australia
It is with pride that I reflect on our proud history of supporting Australians with kidney disease and our early beginnings as The Australian Kidney Foundation in 1968. Originating as a nephrologist-led initiative, the Australian Kidney Foundation focused primarily on securing funding for medical research into kidney disease, treatment and prevention. The very first year of our organisation saw the first grants for the Medical Research Program allocated. Since then in excess of $30 million has been raised for kidney research in our search for new developments, treatments and that elusive cure.

In 2014, I am proud to say Kidney Health Australia is a vibrant organisation, that has gone from a single focus in 1968 to one that now encompasses services and programs across our four mission pillars of: education, advocacy, research and support.

As the national peak body, Kidney Health Australia remains proudly independent of government having developed a broad mix of revenues to support our work on behalf of Australia’s kidney community.

It is therefore pleasing to report that in 2013, Kidney Health Australia posted a profit of $998,896 which is a credit to our wonderful network of supporters, partners and donors and to our tireless and hard working staff.

Some of our achievements in 2013 included:
- Commencement of the ‘Supporting Leave for Living Organ Donors Scheme’ on 1 July, 2013
- Changes to the annual cycle of diabetic care requirements for those living with Type 2 diabetes to include of a measure of kidney function
- Launch of the National End Stage Kidney Disease (ESKD) Decision Aid Tool
- Launch of a national Kidney Club
- Completion of the fit-out of our first Big Red Kidney Bus - a long awaited achievement made possible by donated funds through Perpetual Trustees.

The election of a new Federal Government provides new opportunities for collaboration. The development and strengthening of relationships both at Federal and State levels continues to be a major priority as we strive to raise awareness of a disease that is a ‘silent killer’. With 56 Australians dying each day from kidney related disease, our team is committed to ‘maintaining the rage’ on behalf of our kidney stakeholders.
We are indebted to those members of the Australian community who support our events, appeals, purchase tickets in our lotteries, utilise our commercial operations, and purchase our products - your support makes our work possible.

It is always a humbling experience to receive major grant monies or notification of bequest monies pledged to us by individuals and families whose loved ones have passed away. We recognise this is a major decision to make, and we are honoured to be beneficiaries of such generosity creating a lasting legacy for Australia’s kidney community.

With major new projects due to come to fruition in 2014, Kidney Health Australia is poised to penetrate the crowded health marketplace with awareness messages about early detection and prevention as we strive to ‘save and improve the lives of Australians affected by kidney disease’. In order to succeed we need to continue to implement our business strategy that sees the organisation delivering positive financial results from a diverse range of revenue streams.

An organisation is only as good as its people and as CEO I am so proud to say that our talented team of professionals worked solidly in 2013 to deliver on our organisational promises. I thank and congratulate our Kidney Health Australia family of staff for your dedication, passion and hard work. I make particular mention of my Senior Management Team and thank them for their continued commitment to the organisation and the drive we all share to deliver optimal results for our kidney stakeholders.

I would like to offer my sincere thanks to our Chairman, Mr. Vin Harink, and my fellow Directors. Your commitment to Kidney Health Australia and the contribution of your time and expertise to our organisation is greatly valued and appreciated.

Finally, the entire kidney community and all at Kidney Health Australia thank our outgoing Patron-in-Chief former Governor General Dame Quentin Bryce AD CVO for her support of our work during her reign as Australia’s 25th Governor-General of Australia.

Ms Anne Wilson
Managing Director and Chief Executive Officer
Kidney Health Australia

In 2014, I am proud to say Kidney Health Australia is a vibrant organisation, that has gone from a single focus in 1968 to one that now encompasses services and programs across our four mission pillars of: education, advocacy, research and support.
Medical Director’s report

The last decade has seen a revolution in the way in which kidney disease is presented to the public and recognised as a contributing factor to chronic diseases, as well as how it is managed as a clinical entity.

Moderate to severe chronic kidney disease (CKD) can now be regarded as a significant risk factor for heart disease and stroke – equivalent to the risk from high cholesterol or a previous heart attack, and is a more serious risk factor than having diabetes. The second Kidney in Diabetes report, commissioned by Kidney Health Australia, will be released in early 2014 and this will confirm the huge and expanding contribution of diabetes to the burden of kidney disease experienced in Australia.

Kidney Health Australia has been a leader in this revolution of knowledge about CKD. Several pivotal Kidney Health Australia initiatives – including our CKD Strategy Paper (2005), the introduction of eGFR reporting across Australia (2006), and our continuing health professional education program (KCAT, 2001) – have guided Australia into this new world of CKD.

The visibility of CKD in Australia as an important player in the population health arena was emphasised during the release of the landmark Australian Health Survey results late in 2013. The results of this inaugural Government-funded health and biomarker survey were most disappointing in confirming that whilst one in 10 Australian adults were shown to have CKD, only one in 16 of the people with CKD were aware that they had it!

Clearly, we have a long way to go to get us to the optimal scenario where CKD is reduced in frequency, recognised widely, and given a chance to be clinically managed effectively. We await a kidney specific therapy that will impact strongly on CKD outcomes, and in the meantime work at implementing existing evidence based treatments more effectively.
Kidney Health Australia is working on many fronts to enhance the knowledge of the general public, as well as that of health professionals, about CKD. There is still much to be done in ensuring that Australians with kidney failure have equitable and affordable access to treatment programs appropriate for them, and share the decision in choosing their own therapy. The tightening financial belt that is evident throughout the health sector will add to the challenge for Kidney Health Australia in making progress towards that goal in the next year.

A/Prof Timothy Mathew AM
Medical Director
Kidney Health Australia

The visibility of CKD in Australia as an important player in the population health arena was emphasised during the release of the landmark Australian Health Survey results late in 2013.
Our Organisation
This year was a milestone for Kidney Health Australia’s policy and advocacy efforts. Not only did we renew our government relations efforts – we have redesigned our approach and mapped out comprehensively our policy agenda. Through the development of a new Government Relations and Policy Strategy we have laid out what each of our key policy issues are, what we believe are realistic, effective (and economically efficient) implementable solutions and are now pursuing them at haste at both a Federal level, as well as at State and Territory level.

Policy development aside, it was also a year when our efforts started to bear fruit. We advocated for a new approach to the enduring issue of financial strains for live donors, highlighting how the Federal Government could lessen the burden by providing paid leave. In April, the Minister announced the ‘Supporting Leave for Living Organ Donors Scheme’ with Kidney Health Australia. A two year pilot, it will provide 6 weeks paid leave to live donors who are required to take time off from work, meaning they will still have an income while they are recovering. This was followed by the announcement in May by the Minister that, as part of the annual cycle of care for diabetics Practice Incentive Payment (PIP), a measure of kidney function will now be required to be taken by GPs.

It was also a year where we laid out our policy viewpoints – to Federal and State Ministers, Parliamentarians, bureaucrats, policy influencers, the media and the general public. If you visit our policy and advocacy webpage you can review our Federal Budget.

In 2013 we saw a number of successes in the policy space, but there is certainly much more yet to be achieved.
Submissions, our National Action Plan launched during the 2013 Federal election, as well as our responses to the Medicare Local Review and the National Commission of Audit, to name but a few. These submissions have considered a range of critical issues, and canvassed potential solutions for consideration by government – increasing hospital funding; investing in additional GP education; improving patient and carer support; and of course, issues relating to renal health of Indigenous and Torres Strait Islander Australians.

We also lodged submissions to the Queensland, South Australian and Northern Territory Governments regarding their patient assistance transport schemes, recognising that travel is a huge issue for those on dialysis. We saw some improvements announced for South Australia and, in the case of the Northern Territory, the introduction of our key ask: a weekly rather than per trip, travel threshold. At a State level, we have continued to press the case for improved rebates for home dialysis patients to address the out of pocket costs for electricity, water and associated set-up costs, and in the case of Tasmania were able to address issues around staffing of a local renal unit.

We have also worked hard to link our policy and advocacy to a concerted media plan; to ensure that our profile remains ‘front of mind’ for policymakers when it comes to kidney policy. To that end, we continue to work closely through a number of key alliances – such as the Australian Chronic Disease Prevention Alliance and the National Vascular Disease Prevention Alliance – bringing together the peak health organisations to advocate jointly, thereby improving our chances of success.

In 2013 we saw a number of successes in the policy space, but there is certainly much more yet to be achieved. To that end, Kidney Health Australia will be expanding its Government Relations and Advocacy unit, and in 2014 seek to focus on addressing many of the issues that reside at a State and Territory level.

Health
Mrs Anne Revell
General Manager Health Programs & Services

Kidney Health Australia’s Health team is responsible for the provision of services and programs around the nation that underpin the key areas of education, advocacy, research and support. In 2013, the health calendar offered a number of highlights – including the integration of local health promotion events in conjunction with our annual Kidney Kar Rally fundraiser. This saw information and education around kidney health being delivered to the general community at local football games, in key shopping areas, and very successfully at local schools in rural towns from Tamworth to Bundaberg and back to Armidale.

Essential to our information and education provision, the Kidney Health Information Service (KHIS) continued to provide support, information and referral to over 2,000 callers. Highlights in education have also been the expansion of the collaborative chronic disease Community Education model with successful delivery in Tasmania.
Continuing in education and health promotion, another achievement was being invited to deliver an Indigenous Health festival, the “Take Care of Yourself Festival...healthy kidneys, healthy heart, healthy blood” in Wadeye, Northern Territory. With week-long activities and a community afternoon full of music, culture and dance this was a special event, both in its collaborative approach and the engagement from the community – particularly in embracing one of the key health messages ‘drink Wadeye water’.

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 partner with the Royal Adelaide Hospital to deliver the social and peer support aspect of a Young Adults Program, which caters for young adults 18-26 and has already shown resounding levels of participation and effectiveness.

The well-established Henry Giblett Adult Holiday Dialysis program in Busselton, Western Australia yet again proved to be extremely successful, with a record number of 25 families registering to take part. And finally, in 2013, we were also very proud to publicly recognise 34 new recipients of our esteemed Operation Angel Awards, which honour the outstanding people who have made exceptional contributions to the kidney community.

Medical Programs
A/Prof Tim Mathew
Medical Director

In 2013 the Medical team continued to be committed to producing high-quality, evidence based, resources for health professionals and consumers, designed to improve awareness and understanding of early detection and
management of CKD. We have just published the 8th edition of “Living with Kidney Failure” – a book written for people confronting their pathway and choices of treatment with established kidney failure. In addition, the current edition of our GP booklet on CKD Management has now had 35,000 copies printed and distributed in primary care over the last two years, and we are committed to a new edition in 2014. Work has also started on a national survey of general practitioners to assess their attitudes, knowledge and practice in the area of CKD. This survey will also serve as an evaluation of the KCAT program, now in existence for over a decade.

Outcomes from the survey will be instrumental in guiding future health professional education initiatives and Kidney Health Australia early detection and management programs.

The substantial educational work in the pre-dialysis space – funded through a Government grant – is beginning to bear fruit, with a suite of resources for health professionals and consumers launched mid-year, and health professional education workshops ongoing. In 2013, Kidney Health Australia also expanded the Kidney Cancer Support and Information Service, with a dedicated website and patient information pack.

Commercial Operations

Anne Wilson
Managing Director, CEO

The 2013 year saw the trialing of a new corporate structure that placed all of Kidney Health Australia’s revenue generating activities under one national business unit – Commercial Operations. Many new initiatives were implemented in our Call Centre, which led to greater efficiencies and opportunities for new product development and partnerships.

Changes to our lotteries structure meant that the Call Centre conducted four National Lotteries in 2013, with a further four Western Australia lotteries successfully completed and drawn before year end in 2013. Our dedicated Call Centre staff does a tremendous job in lotteries and our commercial operations of Solution K and KHA Comms.

Work in the events, marketing and communications areas resulted in improved awareness for our major events throughout the year. These included our Big Red Kidney Walk held on Father’s Day, and our 25th Kidney Kar Rally held in August. Both these events raise much needed funds for our national Kidney Kids Programs and showcased the challenges faced by people with kidney disease across all forms of media.

Our kidney specific multivitamin KidneyVital has continued to be accepted onto pharmacy shelves in hospitals in two states in Australia – Queensland and Victoria – and we are very excited to be launching a new product for kidney health monitoring in mid 2014. Both of these new products help us to raise awareness of chronic kidney disease in the wider community, which is critical for reaching the 1.7 million Australians with chronic kidney disease.

2014 is shaping up to be a very exciting year for Commercial Operations at Kidney Health Australia, and I thank my Commercial Operations team – many of whom only joined us in 2013 – for a solid year delivering some very pleasing results against a challenging and competitive not-for-profit marketplace.
Our Organisation

Corporate Services
Ms Rosanna Caré
Chief Financial Officer and Company Secretary

The Corporate Services Business Unit is responsible for supporting and guiding the organisation. By partnering with Senior Management and key stakeholders, Corporate Services is able to steer Kidney Health Australia to achieve its priorities.

During 2013, Kidney Health Australia’s ongoing financial stability remained a key focal point. Corporate Services Key Performance Indicators include measures on the timely distribution of financial information in order to support the organisation in its decision making process.

We achieved another great result in 2013; however there is always scope for improvement. The Corporate Services Business Unit’s objective is to support Kidney Health Australia’s delivery of high-quality services, advocacy, research and Commercial Operations outcomes through responsive and efficient corporate support.

Corporate Services have the capacity to proactively respond and drive future direction, to ensure targets are met via effective engagement with Senior Management.

Kidney Health Australia’s annual planning and Budgeting process strengthens the strategic planning capability and ensures successful delivery of Kidney Health Australia’s priorities.

The long term financial stability of Kidney Health Australia underpins its ability to expand and achieve its strategic goals. Whilst this has been achieved in recent years through the collective and collaborative approach of the Senior Management Team, this could not have been executed without the support of the Corporate Services Business Unit.

We cannot however rely on the outcomes of prior years to meet our future needs, as the economic outlook for 2014 suggests we have another tough year ahead of us. The Corporate Services Business unit will continue to provide the tools, timely data, direction and proactive support to ensure Kidney Health Australia achieves its priorities for 2014.
Business Strategy
Our Programs
Education
Kidney Check Australia
Taskforce (KCAT)

Ms Breonny Robson

Established in 2001, the Kidney Check Australia Taskforce (KCAT) aims to improve health outcomes for Australian’s living with kidney disease through educating health professionals about the disease. 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 working in primary care.

KCAT once again had a highly productive year in 2013. Throughout the year, KCAT conducted 103 face-to-face education sessions for Australian Health professionals. This saw over 2600 GPs, Nurses, and other health professionals educated on the detection and management of kidney disease. This is quite an achievement for the program and is the first time we have run over 100 sessions in a single year since the program’s inception.

In addition to the interactive workshops, KCAT continues to expand into alternative methods of education delivery to meet the diverse needs of Australian health professionals. In 2013, KCAT offered two online learning modules on CKD Management, and also ran a series of webinars, to provide practical access to high quality kidney disease education in a user-friendly way. These initiatives were accessed by over 1000 health professionals.

Participants of KCAT education sessions continue to give very positive feedback from all of our education sessions. Ninety per cent of workshop participants rated our education as highly relevant to their practice, and also rated their learning needs as entirely met by the education provided.

KCAT continues to develop new teaching materials so as to remain at the forefront of CKD education in Australia. In 2013, KCAT launched four new face-to-face education modules, as well as new online learning activities. This led to additional interest in the program and was instrumental in achieving the positive results for 2013. Constant revision and development of new modules ensures that the educational workshops remain current and relevant to participants.

Throughout 2013, KCAT continued to build relationships with a variety of stakeholders including various health professional colleges and bodies, health professional training organisations, Medicare Locals, and health services 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.

To further the KCAT message, we have participated in major GP and nurse conferences by running education sessions on kidney disease, and have also had abstracts accepted and presented at a number of major peak body national conferences.

The guidelines booklet ‘Chronic Kidney Disease (CKD) Management in General Practice’ continues to remain a sought after publication by primary care health professionals – in 2013 we distributed over 4,500 copies and demand remains strong.
Volunteer support is critical to the success of KCAT, and we are grateful for the continued endorsement from the nephrology and nursing communities. We would like to thank all the Nephrologists and Renal Nurses who have kindly donated their time and expertise in presenting KCAT workshops in 2013. Our presenters continue to be extremely well received with excellent participant feedback and evaluation scores across the board.

Home Dialysis and End-stage Kidney Disease (ESKD) Education Projects
Ms Debbie Fortnum

The ESKD education project has completed its first phase of identifying the need for and developing additional educational tools. A shared decision making tool titled ‘My Kidneys, My Choice’ was completed by a collaborative group. A DVD for peritoneal dialysis, simple photo information sheets, translated treatment option fact sheets, a home dialysis booklet and multiple online learning packages for health professionals were all completed by the Kidney Health Australia project team with consumer and other stakeholder input.

The tools were all launched at the Renal Society of Australia’s Annual Scientific Meeting in June 2013. Since then, direct education to health professionals has been provided in 10 workshops, covering every state and territory, totaling 200 health professionals and numerous site visits and teleconferences, whilst three presentations and five posters have been displayed at conferences. Feedback is excellent, with many units already using or intending to use the ESKD project tools.

Monthly newsletters continue to be produced for a constantly growing network in relation to home dialysis and the ESKD project. Research has started to evaluate the primary tools for the project, including a multi-site survey for the decision aid tool.

Community Education & Awareness
Mrs Anne Revell

Consumer education and community awareness continued to be a major focus in 2013 with events, displays and activities held nationally over the year ensuring direct exposure of key health messaging to over 9,500 people.
Kidney Consumer Education Forums

A total of 55 participants attended the October ‘Keeping informed about our Kidneys’ forum held in Penguin, Tasmania. Presentations were heard from a range of health providers – a diabetes health educator, physiotherapist, nephrologist, podiatrist, social worker, chronic kidney disease nurse educator and Consumer Committee members.

Topics covered home therapies as a treatment option, living with chronic kidney disease and consumer experiences, understanding diabetes and your kidney health, mindfulness-based stress reduction, the benefits of caring for your feet and a session on ‘Be active, Be healthy’.

Evaluation feedback from this forum was extremely positive and constructive, with attendees indicating they strongly identified with the presentations by patients with chronic kidney disease who shared their stories, and that they had gained insight and practical suggestions to help them better manage their own health picture.

In Perth, the Western Australian Renal Education Services (WARES), a partnership between Kidney Health Australia, Sir Charles Gairdner Hospital, Royal Perth Hospital and Fremantle Hospital delivered four free education seminars over the year to people living with kidney disease. The sessions promoted self-management and highlighted healthy lifestyle behaviours and treatment options for end stage kidney disease through interactive presentations and patient stories.
General Public Community Education Forums

After two years of trialing and evaluating the General Public Kidney Health Forums ‘Linking kidney health, heart health, blood pressure and diabetes’ in Victoria, this education model was replicated in Tasmania with the encouragement and support of Kidney Health Australia’s Tasmanian Consumer Committee. Funding from Hare Forbes Machinery House and Tasmania Medicare Local, together with community partnerships with Stroke Foundation, Heart Foundation, Diabetes Tasmania and Cancer Council Tasmania, ensured a collaborative and successful day.

Several new initiatives also added to the experience and outcomes, including holding the Forum on a Sunday, which resulted in an increase in the number of full-time working adults who attended and, with 11% of attendees aged between 21 and 44 years old, it also provided the opportunity to connect with a younger audience.

Indigenous Health Education

Kidney Health Australia with the support of MusoMagic held the “Take Care of Yourself Festival...healthy kidneys, healthy heart, healthy blood” in Wadeye, Northern Territory in June 2013. A remote community located 320km south-west from Darwin, Wadeye has a population of approximately 2,500-3,000 and is the largest Aboriginal settlement in the Territory.

The Festival focused on sharing health promotion messages through song, dance and stories; 450 people took part and feedback from the community has been very positive.
The local children loved Billy the Kidney, the fun ‘scientists’ who demonstrated how kidneys work, as well as the experiments and health promotion messages in the school during the week and at the Festival. A wonderful lasting outcome of this project is a ‘Look after Yourself’ music video featuring local children and Billy the Kidney, which has been uploaded to Kidney Health Australia’s YouTube channel and website.

The Festival was supported by financial assistance from the Australian Government, Kindred Spirits Foundation, Victoria Daley Shire Council NT, Top End West Development, NT Health and Renal Services NT Health. Community partnerships and in kind support was received from Palngun Wurnangat Association, Our Lady of the Sacred Heart Thamarrurr Catholic College, Catholic Care Wadeye, Health Clinic Wadeye, Cotton On Foundation and the Jimmy Little Foundation.

**Kidney Kiosk**

The official launch of Kidney Health Australia’s pilot Kidney Kiosk project took place on World Kidney Day, 14th March, at Cairns and Hinterland Hospital and Health Service.

The Kidney Kiosk is an interactive program designed to encourage patients with kidney disease to self-manage their illness. The touch screen kiosk is portable and allows patients to access up-to-date information on nutrition, Indigenous health, and further resources for self-management. Each of the nutritional presentations are delivered by an on-line presenter, who clearly explains the concepts in easy to understand terminology. The kiosk can also be set up in waiting rooms for training purposes.

This pilot project was funded with assistance from the Queensland Department of Health, and is currently located in both Cairns Base Hospital and Townsville Hospital (North Ward Health Campus).

**Translation Project**

In 2012 the inaugural Kidney Health Australia Translations Project received $20,000 from the Joe White Bequest. A comprehensive report was issued which then elicited further funding of $20,000 in 2014. This funding enabled an expansion on the 2012 translations project, increasing the number of different resources available in community languages. The focus for translation was on fact sheets surrounding treatment options and nutrition and there are now a total of nine fact sheets translated into 20 different community languages including Chinese, Greek, Italian, Vietnamese and Arabic.
The local children loved Billy the Kidney, the fun ‘scientists’ who demonstrated how kidneys work, as well as the experiments and health promotion messages in the school during the week and at the Festival. A wonderful lasting outcome of this project is a ‘Look after Yourself’ music video featuring local children and Billy the Kidney, which has been uploaded to Kidney Health Australia’s YouTube channel and website.
Advocacy
Advocacy

Government Relations

A key achievement of Kidney Health Australia’s advocacy efforts was the introduction of the ‘Supporting Leave for Living Donors’ Scheme. Some countries overseas provide financial reimbursements for the out of pocket costs for those who chose to become live organ donors. Kidney Health Australia has advocated, alongside of and on-behalf of living donors, for the removal of such financial barriers through the introduction of paid leave. As many living donors have exhausted their leave arrangements, they are often required to take unpaid leave. On 7 April 2013, the Minister for Health, with Kidney Health Australia announced the introduction of a 6 week paid leave scheme, with leave paid at the minimum age rate. The current scheme is a two year pilot, commencing 1 July 2013, after which the Government will reassess it.

Following the announcement of the scheme, Kidney Health Australia has embarked on a communication and education campaign to make living donors aware of this support, including briefing sessions in most state and territories, a dedicated online comment book, social media and ongoing engagement with the Federal Department of Health.

Above: Anne Wilson, Kidney Health Australia CEO, and The Hon. Tanya Plibersek MP, then Minister for Health, announce the launch of the Supporting Leave for Living Donors Scheme.
National Advocacy

With so much of the health system either funded, or overseen, by the Federal Government, a strong advocacy presence is critical. To that end, Kidney Health Australia again held the launch of Kidney Health Week in Australian Parliament House, Canberra in 2013. The event, launched by the Health Minister and the Shadow Minister for Health, saw a turnout of over 80 guests. It also coincided with the policy announcement by the Minister that a measure of kidney function will now be included as part of the Diabetes Annual Cycle of Care Practice Incentive Payment (PIP).

Our presence in Canberra has also involved a number of meetings with the Ministers, Shadow Ministers and the full range of Parliamentarians on a range of issues. This has been supplemented with extensive engagement with the Department of Health on issues such as: the need (and subsequent undertaking of) a living donor study, the need for a new Chronic Disease Strategy, improved food labelling, and renal service delivery issues.

Finally, Kidney Health Australia has continued to raise kidney issues within the context of broader health policy changes, including but not limited to: the development of a National Aboriginal and Torres Strait Islanders Health Plan; the Medicare Local Review, the Commission of Audit and Activity Based Funding. On the latter, Kidney Health Australia has played a close and continuing role in advocating to the Independent Hospital Pricing Authority as they determine the manner in which federal funding will support dialysis nationally. Of course, our involvement in research continues, most notably through work being undertaken by the Australian Bureau of Statistics and the Australian Institute of Health and Welfare.

Our presence in Canberra has also involved a number of meetings with the Ministers, Shadow Ministers and the full range of Parliamentarians on a range of issues.
Advocacy

Policy Platforms

Successful advocacy for change requires presenting a strong thought-out plan, highlighting not only the issues that require addressing, but workable solutions. In 2013, Kidney Health Australia put forward two key documents designed to raise kidney disease in the minds of policy makers. The first was our Federal Pre-Budget Submission and the second was titled ‘Tackling Kidney Disease: A National Action Plan to Reduce Australia's Kidney Disease Burden’, released during the Federal Election Campaign. In addition, it was sent to each of the major parties to highlight the need for improved kidney policy. Both these policy platforms are available on our website, and they put forward proposals spanning the entire health system - from federal strategies, funding and early detection through to organ donation policy and support.

Of course, through our membership on the AOTA Advisory Council and the NSW Organ and Tissue Donation Service Implementation Liaison Group, we continue to work with both the Federal and NSW Governments regarding their organ donation agendas.
Advocacy at a State and Territory Level:

The other half of advocacy to Government is Kidney Health Australia’s work with State and Territory Governments. In particular 2013 was a busy year in advocating changes to the raft of differing Patient Assistance Travel Schemes. Providing reimbursements for private travel and accommodation costs incurred to attend specialist medical services is particularly important for dialysis, due to the high frequency of trips - a minimum of three times a week. Kidney Health Australia submitted a number of papers to reviews being undertaken in South Australia, the Northern Territory and Queensland. In particular, we pressed the case for the introduction of a weekly ‘threshold’ distance figure for dialysis patients. Currently patients are only eligible in many States if they travel over a certain distance ‘one way’, leading to a case where a dialysis patient may travel a great distance per week (due to the high frequency of dialysis) but remains ineligible. While we await an outcome from the Queensland Government review, we did see some improvements announced in South Australia, and in the case of the Northern Territory, a $7.5 million dollar injection and the creation of a weekly threshold figure.

Kidney Health Australia has also continued to press the case for improved reimbursements for home dialysis patients to better cover their out of pocket costs. We have also argued for improvements to renal dialysis service delivery, most notably in Tasmania where we saw the decision to increase the staffing allocation to a dialysis unit, meaning that Tasmanians could dialyse closer to home.

Finally, Kidney Health Australia continues to be involved in discussions around kidney policy and service delivery - such as in Victorian where we saw significant policy development, through our bringing together of the Chairs of each Renal Clinical Network, and through our relationships with renal units and health departments.
Advocacy

Alliances for Advocacy

A key plank of our advocacy approach has been to work in alliances. The Australian Chronic Disease Prevention Alliance (ACDPA) brings together Kidney Health Australia, the Cancer Council, the National Heart Foundation, the National Stroke Foundation and Diabetes Australia. Through our alliance with ACDPA we have advocated for a number of key areas around healthier food choices - such as a front of pack labelling system (Health Star Rating). In addition, through an alliance with a number of other peak health organisations we have worked to raise awareness around high sugar drinks and promoting healthier alternatives.

Through the National Vascular Disease Prevention Alliance (NVDPA) we have advocated jointly on the merits of an Integrated Health Check. Additional State and Territory alliances have focussed on a range of issues, including patient travel, while through the HOME Network of renal nurses, we have examined issues regarding home dialysis costs. We have started also working with like-minded organisations on a number of fact-sheets - in 2013 this was with the National Rural Health Alliance to develop an information resource on kidney disease in rural areas.
National Consumer Council

The National Consumer Council consists of a chairperson from each of the State and Territory Consumer Committees. Consumer Committee representatives bring a wealth of experience, including their own personal histories with kidney disease, dialysis or kidney transplants; or perhaps have been a carer, a nurse, or – in some cases – a kidney specialist.

The National Consumer Council advocates for the key points outlined in its position statement released in 2010: *The impact of kidney disease and what Government should be doing about it*, which identified the need for:

- adequate dialysis capacity that enables patients to:
  - access and choose from a full range of treatment options in their local area
  - 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 are required to routinely 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 twice in 2013, with discussions focusing on organ donation rates, adequate electricity subsidies for home dialysis patients, payments for carers and reimbursement for out-of-pocket expenses for living kidney donors.

The National Consumer Council was also delighted to maintain an Urban Indigenous Consumer Representative and, in a landmark meeting, welcomed two Indigenous members from the newly formed Northern Territory consumer group to the Council for the first time.
State and Territory Consumer Committees

State and Territory Consumer Committees continued to be proactive in identifying and tabling issues for people living with kidney disease throughout the year and providing valuable consumer insight to policy submission. They also generously assisted Kidney Health Australia with the delivery of key education and awareness events. Specific activity for each Committee is detailed below:

Victoria

The Victorian Consumer Committee has been very proactive in continuing to support Kidney Health Australia in assisting with educational and health promotion opportunities and the delivery of key events such as the Werribee Kidney Health Forum...linking kidney health, heart health, blood pressure, stroke and diabetes and the Big Red Kidney Walk. They have also regularly volunteered for interview on radio and in print media at very short notice.

New South Wales

The major focuses of the NSW Consumer Committee in 2013 were addressing costs and equity regarding home dialysis wiring standards and rebates, initiating a review of the Taxi Subsidy Scheme and a NSW transplant accommodation review. The committee had a presence in all NSW major events including Operation Angel held at Customs House, the Big Red Walk at Tumbalong Park, the Kidney Kar Rally in Tamworth, as well as assisting with the development of new Kidney Health Australia resources.

South Australia

In 2013, the South Australian Consumer Committee (SACC) advocated on key issues, which has resulted in current reviews of VRE protocols and transport assistance for dialysis patients. The SACC continued to support the SA Kidney Club, Operation Angel Awards and assisted with the Big Red Kidney Walk.

Past and present SACC members should also be congratulated on establishing the Kidney Coffee Club which meets once a month as a consumer driven group, and has received very positive feedback.

Western Australia

In 2013, the West Australian Consumer Committee (WACC) helped to organise a bigger and better Big Red Kidney Walk and began investigating options for supporting WA patients to access holiday dialysis.

The Committee also recruited a satellite dialysis nurse to help keep them informed of any issues regarding transport and parking issues identified by dialysis patients, and started to gather data about parking fees at WA hospitals, as the rising cost of parking is becoming a major issue for WA patients.
**Tasmania**

The increased involvement of consumers in the Tasmanian Consumer Committee and participation in KHA programs such as the Harley Owners group, Big Red Kidney Walk and KHA Tasmanian Consumer Forum has provided a stronger network and increased capacity for consumers to be involved in raising awareness of kidney health issues and support to consumers and families at the local level.

The Tasmanian Consumer Committee has increased its membership and has undertaken training in community awareness, public presentations and volunteer support through the TelEConnect program. It has been pro-active in promoting KHA events and media events and has also been involved in supporting local rural communities by increasing kidney health awareness with local service groups and clubs.

**Northern Territory**

Kidney Health Australia welcomed the formation of a Northern Territory Consumer group in 2013. This new group is evolving into an important representation of the diverse Northern Territory population and the particular issues they face. Already we have seen the potential relationships this group can bridge between health professionals and the community, and we have been delighted to host two key members at a National Consumer Committee meeting.

**Queensland**

Throughout 2013 the Queensland Consumer Committee was extremely active in supporting Kidney Health Australia by participating in local health promotions and events, including the Big Red Kidney Walk and Kidney Health Week awareness promotions. It also provided valuable input into policy submissions and education collateral, as well as attaining consumer representation positions on a wide range of local health committees and attending consumer consultation days.
Research
Our Research

Research has always been one of the prime activities of Kidney Health Australia. Over the years it is estimated we have awarded over $30 million to Australian kidney researchers including a number of one million dollar awards, following the Bootle bequest in 2004. The allocation of available research funds has been by competitive application by investigators in their field of interest for scholarships and grants, and some special project funding including for the ANZDATA Registry.

There has been a building view that the available funds for research allocation might be substantially increased by identifying specific areas that would be attractive to the corporate sector for funding. This approach, combined with a sustained effort to accumulate assets in a special research fund which would in time be self-supporting, led the Kidney Health Australia Board to establish the Australian Kidney Research Foundation in the past 12 months. It was considered that this initiative would require its own advisory committee to prioritise funding and hence the long standing Medical and Scientific Advisory Committee, which had held the responsibility for advising the Board on medical and research matters, was disbanded in November. For 2014, it is planned to continue the present arrangements for funding research, however the transition to the new model will occur within the next couple of years.

Grants and scholarships awarded for 2013

A total of 34 applications were received by Kidney Health Australia for funding support in 2013. Our Medical and Scientific Advisory Committee awarded 15 separate grants and scholarships to the value of $488,000 to kidney-related research projects in University departments, medical research institutes, and hospitals throughout Australia. Support to investigator driven research totaled $363,000 plus an additional $75,000 funding for strategic targeted research.

Biomedical Scholarships

The new direction of Kidney Health Australia research funding aimed at a public health agenda included the withdrawal of new biomedical 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 2013, one Biomedical Scholarship was awarded continued funding and three were newly awarded scholarships. Funding allocated was valued at $116,000. 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 through providing sponsored scholarships. 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 Committee for consideration.

**Continuing PhD scholar for 2013**

**Dr Veena Roberts**  
Supervised by Dr Karen Dwyer (Medical)  
St Vincent Hospital, University of Melbourne VIC  
*Reducing chronic kidney disease scarring*

**Newly award PhD scholars for 2013**

**Dr Qi Cao**  
Supervised by Prof David Harris (Science)  
Westmead Millennium Institute, University of Sydney NSW  
*Defining the role of the major subsets of renal mononuclear phagocytes*

**Miss Brooke Huuskes**  
Supervised by A/Prof Sharon Ricardo (Science)  
Monash Immunology and Stem Cell Laboratories, Monash University VIC  
*Investigating the use of stem cells in conjunction with anti-fibrotic treatment to reverse scarring of the kidney*

**Mr Thomas Rogerson**  
Supervised by Dr Angela Webster (Science)  
The Centre for Kidney Research, The Children’s Hospital Westmead NSW  
*Evidence based testing and outcomes in renal transplantation*
Project Grants

Project grants worth $45,000 each for use over 1-2 years. The competition was strong and most applications were considered suitable for support should more funds be available.

Dr Karen Dwyer et al
Department of Nephrology - St Vincent’s Hospital Melbourne VIC
Pre-diabetes in patients with chronic kidney disease

Type 2 diabetes mellitus (T2D) results from a complex interplay between hereditary and environmental influences resulting in an increase in insulin resistance and the inability of the insulin-producing β-cell in the pancreas to secrete sufficient insulin. Recently a severe reduction in biological incretin effect has been recognised as a mediator of this β-cell dysfunction. The incretin hormones are intestinal hormones released in response to nutrient ingestion. Both hormones enhance glucose-induced insulin secretion from the beginning of a meal, the incretin effect. Unrecognised pre-diabetes in patients with chronic kidney disease (CKD) is common (up to 69% in a Turkish population, Basturk & Unsal 2011) and insulin resistance can be demonstrated in patients with CKD and increases as renal function declines. However, there is limited data on the incretin effect in CKD. Cardiovascular events remain the single biggest cause of death of patients with CKD. In the general community an increase in insulin resistance has been associated with incident cardiovascular events. Further in both the general and renal transplant populations pre-diabetes is a potent risk factor cardiovascular mortality. This project will determine the prevalence of unrecognised pre-dialysis in an Australian cohort of patients with CKD and examine the biological incretin effect in these patients. The advent of novel anti-diabetic therapeutics that augment the incretin effect and which are safe to use in patients with CKD, may improve the metabolic and cardiovascular risk profile in these patients.

A/Prof Martin Gallagher et al
Renal & Metabolic Division, The George Institute for Global Health NSW
Using novel health service data to improve the outcomes of dialysis patients

Increasing numbers of Australian patients and families are bearing the burden of dialysis. The outcomes for these patients remain poor, driven in part by factors such as dialysis preparation and the type of dialysis used. Our understanding of how health services impact upon these outcomes has been limited by the absence of an effective means of collecting and analysing data from the outpatient sector. This project will undertake a ‘proof of concept’ expansion of the ANZDATA Registry to include data from the outpatient and hospital sector and use this to understand how outpatient resource use impacts upon patient outcomes.

Dr Meg Jardine et al
Renal Division, The George Institute for Global Health NSW
Impact of salt reduction on proteinuria

Reducing dietary salt may reduce albuminuria, a risk factor for both heart and kidney disease, although this has not been proven. The largest randomised trial of salt reduction worldwide is due to conclude in 2013 and will definitively establish the impact of dietary salt reduction on high blood pressure in 2700 high risk people from rural China. This application proposes to measure albuminuria and measures of kidney function in these participants at the end of the study. The impact of salt reduction on kidney
function and albuminuria will therefore be clearly established. As the largest salt reduction trial ever undertaken, this proposal provides a unique opportunity to establish the role of a cheap and widely available intervention on the kidney. The results are likely to be of high impact within the medical and public health community.

Prof David Johnson et al
The University of Queensland QLD
A study investigating the role of biological markers in determining peritoneal injury in peritoneal dialysis (PD) patients

PD uses exchange of solutions against the patient’s own peritoneal membrane and is the predominant form of home-based dialysis. Despite its simplicity, cost-effectiveness and numerous advantages compared with haemodialysis, PD is underutilized. A major barrier to greater uptake is progressive peritoneal membrane injury by conventional PD solutions with ‘unfriendly’ features. Although there are no markers available to readily identify patients at higher risk of peritoneal injury, MMP-2 is a strong candidate. The aim of this study, which involves international collaboration with a leading expert in the field of peritoneal membrane injury (Prof Nick Topley), is to demonstrate the pattern of serial MMP-2 levels and its association with clinical outcomes in patients receiving conventional or novel biocompatible solutions. The study will use samples obtained during the baIANZ trial, a multi-centre study of biocompatible versus conventional PD solution in 185 new PD patients over 2 years. If MMP-2 is able to accurately identify PD patients ‘at risk’ of peritoneal injury, it may prove to be an invaluable tool for clinicians allowing timely intervention, improved quality of life on dialysis and enhanced access to patients to home dialysis.

Dr Allison Tong et al
Sydney School of Public Health, The University of Sydney NSW
Investigating barriers and disparities in kidney transplantation

Kidney transplantation improves life expectancy and quality of life in patients with end-stage kidney disease compared with being on dialysis. However, the wide variation in living kidney donation rates across Australia remains unexplained. This study will identify a range of barriers and reasons for the disparities in the rates of living donor kidney transplantation. National surveys will be administered to adults eligible for a kidney transplant to assess the associations between socio-economic factors with knowledge about living donor kidney transplantation and identification of potential live donors. A survey will be conducted in all transplant centres to assess the relationship between centre characteristics and the probability of living kidney donation. Qualitative interviews will be conducted with patients and clinicians to gain a range of depth of insight about perceived barriers and disparities in living kidney donor transplantation. The findings will inform targeted efforts for reducing disparities in living donor transplantation.
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.

Three nursing grants were awarded with the scholarships valued at $3,000 each, for a maximum of three years – a total of $9,000 for the 2013 calendar year.

Mrs Wendi Bradshaw  
Master in Nursing Practice  
Deakin University, VIC

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

Ms Anthony Perkins  
Master of Nursing - Advanced Practitioner  
University of Newcastle, NSW

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 was awarded funding for 2013.

Miss May Wong  
Supervised by Prof Carol Pollock  
Kearnes Facility, Kolling Institute of Medical Research, Royal North Shore Hospital, NSW  
The role of anti-inflammatory agent in renal fibrosis

Targeted or Strategic Research

In 2013, an amount of $75,000 was awarded by the Medical and Scientific Advisory Committee 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 2013, Medical and Scientific Advisory Committee (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 2013
Prof David Johnson, the University of Queensland, QLD

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 2013 winner(s) of the Clinical and Laboratory Research Presentations – TSANZ Scientific Meeting

Winners for 2013 were:

Clinical Research Presentation 2013
Ms Melanie Wyld, The University of Sydney, NSW

Laboratory Research Presentation 2013
Ms Stacey Walters, The Garvan Institute of Medical Research, NSW

Kidney Health Australia Priscilla Kincaid Smith Medal

This prestigious biennial award, given only periodically, is the highest scientific accolade of Kidney Health Australia. It is awarded on the recommendation of MSAC for outstanding contributions to the cause of nephrology. No awards were given in 2013. The next award will be presented in 2014.

Past winners include:
2012 Professor David Harris
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 Australasians with Renal Impairment Guidelines

Caring for Australasians 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. For the last 3 years the CARI process has been funded by KHA and late last year it was agreed to continue the funding for another 12 months. CARI continues to develop new Guidelines, review existing ones, and writing commentaries on overseas Guidelines.

New Guidelines

Cardiovascular Disease
Diagnosis and Treatment of Urinary Tract Infection in Children
Infectious Diseases in Renal Units
Autosomal Dominant Polycystic Kidney Disease

Updated Guidelines
Peritonitis Treatment and Prophylaxis
Vascular Access
Iron

Adaptation of KDIGO Guideline
Acute Kidney Injury

Commentary on KDIGO Guideline
Blood Pressure Management in CKD
Lipid Management in CKD

Implementation Projects
Improving the quality of nephrology care in rural Australia: Implementation of the CARI Iron guideline into clinical practice in rural or remote nephrology practices

Peritoneal Dialysis Implementation Project:
Preventing Infection in New PD Patients

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 2013 from Amgen, Roche, Baxter and Shire.
Support
Kidney Health Week

Kidney Health Week is a national awareness campaign promoting good kidney health, held annually in the last week of May (26 May – 1 June). The chosen tagline for this year’s Kidney Health Week represented the serious risk chronic kidney disease has on the health of Australians. The tagline was ‘1 in 3 Australians is at increased risk of kidney disease. Undetected, untreated kidney disease is a silent killer.’

A range of collateral was developed to tie in with this tagline and mailed to renal units, medical centres and members of our kidney community, helping promote this important message. The Health team also supported the campaign, engaging local communities to help spread the word about good kidney health.

A national launch was held at Parliament House Canberra, attended by the Federal Minister for Health, the Hon Tanya Plibersek MP and the Shadow Minister for Health and Ageing, the Hon Peter Dutton MP. At this launch Minister Plibersek announced that the addition of a kidney function test to the annual cycle of care for those with type 2 diabetes under the Practice Incentives Program, which would commence on 1 October 2013. Over 80 parliamentarians and distinguished guests joined us for the day at Parliament House.

Kidney Health Week highlighted the need for greater awareness by urging Australians to take an online risk assessment for kidney disease at www.kidney.org.au. There was a strong media presence resulting in 63 broadcast and print clippings.
**World Kidney Day**

March 14 2013 marked the 8th World Kidney Day. Australia’s theme was ‘Protect your kidneys, save your heart’, specifically chosen to display the strong connection between chronic kidney disease and cardiovascular disease. Kidney Health Australia ran a strong media and promotion campaign during this time, achieving coverage across several mediums.

**Kidney Kar Rally**

Kidney Health Australia’s 25th Annual Kidney Kar Rally crew revved up for an amazing 4,300km journey on August 16th 2013. Over 60 rally teams took part in the gruelling 8-day course, with competitors travelling from Tamworth via Bundaberg and finishing in Armidale. The Rally teams raised a record $600,000 gross prior to the event, plus an additional $14,000 gross at the start dinner auction. Kidney Health Australia staff travelled along the course and hosted events in local towns to raise awareness about kidney disease, a new initiative in 2013. A big thank you to all participants and supporters, including major sponsor Repco.

**Highest Fundraisers:**
1st: Kar 68 – Artline Rally Team – Mike Kluver and Barby Kluver
2nd: Kar 8 – BSLSC – Peter Ward, Graham Ward and Richie Farrer
3rd: Kar 181 The Safari – Tony Tannous, Robert Projeski and Vince Messina

**Outright Winners:**
1st: Kar 11 – The Blues Brothers – Peter Carr and Steve O’Connell
2nd: Kar 508 – Amy’s Team – Robert Cameron and Dean Mosdall
3rd: Kar 26 – Red Baron – Gerard Warrin and Mark Haberfield
Support

Big Red Kidney Walk

Kidney Health Australia’s second Big Red Kidney Walk was a great success. Events were hosted in Adelaide, Melbourne, Perth, Sydney and Launceston on September 1st, and Toowoomba hosted a Walk on September 7th 2013. Additional independent community events were held in Bateman’s Bay, Bathurst, Bega, Collinsville, Darwin, Lillydale and Queanbeyan.

The Big Red Kidney Walk brought individuals, families, teams and members of the health sector together to raise awareness of the impact that kidney disease has on the community, and the need for improved support and research. Participants enjoyed a fun walk through scenic locations, as well as entertainment and a healthy BBQ after the walk concluded.

The highest individual fundraiser was Anne Anderson from New South Wales, who raised $2,450. The highest fundraising team was ‘Team Tennant’ from Victoria, who raised $7,460. Through individual and team fundraising, a gross income of over $94,000 was raised for this event.
45th Anniversary Dinner

Kidney Health Australia hosted its 45th Anniversary and Research Grant Awards Dinner on 28 November at Persimmon Restaurant in Melbourne 2013. This special event was an opportunity to bring leading researchers together and hear from members of the kidney community that Kidney Health Australia research has been able to help. Over 100 special guests were in attendance, ranging from Australia’s leading clinicians and heads of philanthropic institutions, to major donors and members of the research community.

It was a night full of celebrations, acknowledging how far the organisation has come over 45 years and our determination to continue and grow in the future. Over $310,000 of Research and Project Grants were presented to eight recipients.

Kidney Awareness Charity Bike Ride

The Tasmania Chapter of the Harley Owners group held their 8th and very successful event in March 2013. Led by Ken Lawson, the group again did a fantastic job raising awareness of kidney health issues in the local community with over 140 bikes and 200 attendees at the event, which finished with presentations and raffle prizes at Richardson’s in Launceston.

Members of the Tasmanian Consumer Committee were on board helping out on the day and assisting at Westbury with the lunch and the kidney health promotion display at Richardson’s. Through their generosity the group raised $4,100.
**Commercial**

**Solution K**
Solution K is a line of business owned and operated by Kidney Health Australia offering Customer Contact Centre solutions for clients, no matter how big or how small.

Many organisations outsource Contact Centre solutions such as inbound or outbound telephone campaigns and in 2013 Solution K was successful in acquiring new recurring client campaigns as well as providing once-off solutions for other organisations. Solution K also continued to provide campaigns for several long term clients.

In late 2013, changes were made to the organisational structure of Solution K to ensure that it is better positioned to achieve growth and secure new clients in 2014.

**Lotteries**
In 2013 fundraising lotteries provided $1.5m to support the organisation’s programs and continues to be Kidney Health Australia’s most profitable line of revenue.

A new national lotteries structure was introduced in late 2012 and four national lotteries were conducted in 2013 instead of delivering the traditional 12 state-based lotteries. The new national structure did provide some challenges and a number of new approaches were trialled during the year to improve efficiencies and to ultimately increase ticket sales for each lottery. In addition to the four national lotteries, Kidney Health Australia also conducted four Western Australian lotteries in 2013 due to specific permit restrictions in Western Australia.

Direct Marketing was introduced in 2013 to promote the national lotteries to our supporter base. Unfortunately the response rates were disappointing for the associated costs and a decision was made mid-year to cease this type of promotion and to focus on more cost effective options such as electronic direct mail (eDM) or email campaigns.

The consolidation of the state-based lotteries into national lotteries also meant that the total prize pool for these lotteries increased to over $180,000 per lottery whilst the ticket price remained at $50.00.

Fundraising lotteries continues to be a challenging and evolving opportunity. More work is planned in 2014 to improve calling patterns, agent performance and ticket sales per hour to continue to grow this profitable line of business.
Support

FUNDRAISING

Direct Appeals

Our regular donor programs are integral to our fundraising efforts and we greatly appreciate all contributions.

Despite being a somewhat challenging year, we achieved successful results in 2013. Our tax appeal letter featured ‘Maria’s story’ and received an excellent response from our loyal donors.

Bequests

A bequest to Kidney Health Australia can help in many ways, regardless of the amount; it will have a lasting impact on those living with kidney disease. We are sincerely grateful to those who have chosen to leave a lasting imprint by the way of bequests in 2013.

Notable Bequests received:

- $908,000 from the estate of the late Roma Baker
- $702,000 from the estate of the late Alan Tatham

Golf Day

Kidney Health Australia’s Annual Golf Day and dinner was held March 4th 2013 at the Royal Melbourne Golf Club in Victoria. The Golf Day was sponsored by Source Central Partners and Subaru Melbourne. Metro Signs and Metro Partitions both participated as ‘hole sponsors’. There were 23 teams that participated in the golf tournament. Teams included representatives from corporate stakeholders, including Moores Legal, Metro Signs, Metro Partitions, IH Group, AIW, ANZ, CGU Insurance, Imscan-Konica Minolta, Professional Advantage, Infinity, Mills Oakley Lawyers, Filewise and Fourth Wave Wine Partners.

Over 170 participants gathered for dinner following the tournament and heard from inspiring speakers, including mother daughter duo, Tamaryn and Amy Stevens, who shared their story of kidney disease and the Kidney Kids Camps. The dinner included entertainment and a live and silent auction.

The 2013 Golf Day raised a gross income of $82,934.

Our 2013 Tax Appeal letter featured Maria’s story
National Kidney Kids Camp

The National Kidney Kids Camp is a four day peer support and respite program for children living with chronic kidney disease. Due to the medical care that most of these children require, 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 building supportive relationships with others who are living with a similar condition. Camps also provide parents and carers with much needed respite.

The 2013 Kidney Health Australia National Kidney Kids Camp was held in Queensland, at Kindilan Outdoor Recreation Centre, 11th – 14th April 2013. Co-hosted by Royal Children’s Hospital Brisbane under the supervision of Dr Peter Trnka, children 7-17 years living with chronic kidney disease (stage 3 or greater), and their siblings, were invited to join this very special program.

A total of 79 children from Queensland, Victoria, Tasmania, Western Australia, New South Wales and South Australia attend Camp. Accompanied by 16 health professionals from paediatric renal units across the country, the children took part in four days of fun-filled activities under the theme ‘Camp Hollywood’. All Camp participants were also extremely grateful to Australia’s largest indoor amusement centre, Timezone Gold Coast, who hosted a fantastic excursion day at the very last minute, replacing what would have been a rain-drenched day at Movieworld.

A successful addition this year was the return of nine ‘ex-Kidney Kids’ as volunteer carers, who provided a mentoring role at Camp for younger kids to great effect. Feedback on both the Camp and the positive impact it had on some of the Kidney Kids was exceptionally heartwarming. In 2014, Camp will return to the Gold Coast, with attendance numbers expected to exceed 100.

Campers reached new heights in 2013!

Camp is a great opportunity for Kidney Kids to build important friendships.
Support

State Kidney Kids Capers

In 2013, Western Australia hosted three ‘Kids Only Days’ (4th – 6th October 2013) filled with museums, arcades games, laser skirmish, movies and fun parks for all! In total, 24 children and 12 volunteers took part throughout the three days. A major highlight of this year’s program was the reach Kidney Health Australia achieved with new families - some coming from as far as Albany to enjoy the program. The year was capped off perfectly with a ‘Family Fun Day’ to Adventure World with 38 kids and 37 adults attending a BBQ lunch with swimming and rides.

A new national record for attendance was set at our Victorian Kidney Kids Capers (September 21st - 22nd) with 130 people taking part. Day one was a trip to the Royal Melbourne Show and included lunch, rides and entry, a first time visit for some families made possible by Kidney Health Australia.

The ‘Kids Only Day’ proved an even bigger success with six hours of unlimited arcade games, ten pin bowling and laser tag at Melbourne’s biggest indoor amusement park, Galactic Circus.

In New South Wales, 53 children and 52 adults attended their Kidney Kids Capers. A great day out at Luna Park for the ‘Kids Only Day’ had kids exhausted after a full day of non-stop rides, games and entertainment. The ‘Family Fun Day’ venue was a first for the program, a day at the Sydney Cricket Ground to watch the Sydney Swans. Fun was had by all with gifts and goodies for all the children from Sanity who sponsored this day. All families were treated to lunch at the top floor function room before the bounce to round out a very special weekend.
South Australian Kidney Kids Capers was run September 7th - 8th 2013 with great success. 42 kids and 36 adults were in attendance for a day of Laser Skirmish, Ten Pin Bowling and Arcade Games, followed by family fun at The Royal Adelaide Show. We attracted some great new families this year who were all extremely grateful for the efforts of Kidney Health Australia.

In Queensland, 30 children and 18 adults attended the Kidney Kids Capers program from October 19th - 20th. At the ‘Kids Only Day’ on the Gold Coast, 30 kids had a great time at Dreamworld with the support of 10 volunteer supervisors. The ‘Family Fun Day’ at Australia Zoo was enjoyed by all who attended with some fantastic feedback from parents expressing their thanks for the social support.

**Young Adults Group**

In 2013, Kidney Health Australia supported the first Australian Young Adult Kidney Clinic in South Australia. This clinic was established to support 18-26 year olds living with chronic kidney disease. Research has indicated the difficulty this age group faces dealing with a chronic illness and the benefit that peer support has in conjunction with medication and improving lifestyle. Kidney Health Australia staff lead the critical social agenda that supports the clinic, delivering activities to stimulate interaction and conversation amongst the group. Early outcomes from this pilot program, which will grow in 2014, show it to be extremely successful in engaging young adults with their treatment and self management.

**Kidney Club**

In 2013, Kidney Clubs continued to provide a friendly environment where patients, carers and family members could talk openly about their personal experiences. Through the year, 15 Kidney Club meetings were held in seven different locations: Alice Springs, Adelaide, Cairns, Canberra, Darwin, Hobart and Toowoomba. In total, the meetings were attended by 280 people, up from 178 in the previous year. This year we were extremely pleased to launch the Kidney Club in Darwin and Cairns, with each location holding one meeting.

With the guest speakers providing the groups with information of various topics this enabled participants to leave the meeting with knowledge to assist them in becoming better self-managers of their health. Plans for 2014 include formalising the speaker program and testing revised models for sustainability.
Living with Kidney Failure (8th edition)
Dr Marie Ludlow

In 1982, Kidney Health Australia published the first edition of a book called “Living with Kidney Failure”. Designed to be a practical resource for people diagnosed with kidney disease, this book is regarded as the key resource of kidney information written in Australia, for Australians. Over the years, we estimate that more than 20,000 copies of this book have been distributed. In 2013, Kidney Health Australia received support to develop the 8th edition of this vital resource. Guided by a Steering Committee of nephrologists, renal nurses, allied health personnel and consumers, the 8th edition of “Living with Kidney Failure” is aimed at people needing to decide on the treatment options for kidney disease, and presents a carefully balanced view of the choices in type of dialysis and location. The new edition has adopted user-friendly spiral binding and writeable pages, and has an enhanced focus on self-management strategies. We hope that this resource allows people with kidney disease to better understand their condition, as well as improving well-being and health outcomes.

Kidney Health Information Service
Ms Ainslie Bolton

The Kidney Health Information Service (KHIS) 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 2013, KHIS has received in excess of 2,000 enquiries, which reflects an overall increase of 10% from the 2012 period. Primarily, the service is contacted by patients, carers and families affected by kidney disease; many requests regard recent diagnosis, understanding terminology, available management options, transplantation, nutrition and travel support. Across the year nearly 23,000 pieces of educational material (brochures, pamphlets, booklets, posters etc.) were distributed nationally through the KHIS service.

The KHIS service also noted a welcomed increase in contact from health professionals, who are seeking additional information and advice pertaining to CKD. This contact also offers extended opportunities for these professionals to be referred to, and engage with other Kidney Health Australia staff and programs. Enquiries regarding kidney cancer continue to grow.
Kidney Cancer Support and Information Service

Ms Kirren Grennan

Kidney cancer was the eight most common cancer diagnosed, and fifteenth most common cause of death in Australia in 2007 (AIHW, 2012). It is estimated that 3,000 people received a diagnosis of kidney cancer in 2012, and between 1991 – 2009, the incidence of kidney cancer increased by approximately 30%.

Launched in late 2012, the aim of this Kidney Cancer Support and Information Service is to provide support and resources to those people affected by kidney cancer, to support kidney cancer research, and advocate for consumers. The inaugural year of this service produced positive results; the dedicated Kidney Cancer Website (www.kidneycancer.org.au) attracts approximately 1,800 visits every month; a Kidney Cancer Resource Pack has been updated and is now being distributed; and Kidney Cancer Connect, an online moderated support forum, is now available via the website allowing people to share experiences, seek reputable links and obtain relevant information. In addition, the free call or email Kidney Cancer Information Service is expanding and received approximately 55 calls for support over the last six months of 2013. Future direction for the project will look to strengthen health professional relationships and continue to deliver high quality services to the kidney cancer community.

TelEConnect

Ms Colette Lappin

TelEConnect is a national peer support program that connects kidney consumers and carers with trained volunteers that have similar experiences living with, or caring for someone affected by kidney disease. A successful re-launch of the TelEConnect program occurred in October through funding from the National Home Dialysis Project, after considerable consumer interest reflected the need for a reinvigorated peer support service. Two rounds of volunteer training were also delivered and numerous connections made in the short period since the program’s launch. Feedback from people who have participated in the volunteer training, as well as from consumers and carers who have been linked in with the service, has been overwhelmingly positive. Continued promotion of the service, largely through our KHIS line, and additional volunteer training are planned for 2014.
Henry Giblett Adult Holiday Program

Through the generous support of Lotterywest, the Henry Giblett Adult Holiday Dialysis Program was again held November 10th – 17th 2013 in Busselton, WA. Restructuring of the program saw a new record of 25 families invited, none of whom had attended the program before. Over the six days, 75 dialysis sessions were conducted as a collaborative effort between Kidney Health Australia, Fresenius Medical Care, Busselton Hospital, Diaverum, Baxter, Gambro, Western Australian metropolitan dialysis units and St John Ambulance.

The key to the program’s success, a temporary mobile dialysis unit, was again set up in the St John Ambulance Sub-Centre, near the accommodation so that people 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. This program has now supported 205 Western Australian families in having a holiday in this beautiful coastal region.

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.

This year nominations were received from across each state and territory within Australia. Ceremonies were held through the year and across the nation to recognise and honour the 34 successful Operation Angel Award recipients for 2013.

ACT
John Arganese

NSW
Val Courte
Eddie Addison
John Devereux
Moree Renal Committee
Gosford Central Coast Support Group
Pauline Byrne
Bathurst Surf Life Saving Club
Amanda Williams
Sutherland Hospital Satellite Dialysis Unit
A/Prof Josephine Chow

QLD
Martin Chambers
Ada Stevenson
Cesare (Ces) Crispigni
Emma Hart (Ipswich Dialysis Unit)
Dennis Mellican
Bruce Warrell
Michele Harvey (Nephrology Nurse Practitioner- Mount Isa Community & Primary Health Service)
NT
Sarah Brown, The Purple House
(Alice Springs)
The Danila Dilba Aboriginal Health Service
(Darwin)

SOUTH AUSTRALIA
Jill Lawton
Pauline Ingerson

TAS
The Mersey Community Care Association

VIC
Ray Tuhan
Carmel Gordon
Rosebud Holiday Dialysis Program
Karen Manley (Austin Health)
Tina Marangoni
Sandra Bell
Ros Ball
Mechelle Seneviratne (Monash Medical Centre)
Lee Douglas (Royal Melbourne Hospital)

WA
Dr Hemant Kulkarni
Margaret Moore

Anne Wilson, Kidney Health Australia CEO, presents Victoria’s Rosebud Holiday Dialysis Unit with their Operation Angel Award.
Support

Family Accommodation Initiative Transplant Housing (F.A.I.T.H.)

In 2006, two houses were leased by Kidney Health Australia from Foundation Housing to provide accommodation for live kidney donors from rural WA towns. Feedback from major WA hospitals had highlighted the need for patient accommodation for live donors who were often paying for rent or a mortgage back home as well as for the accommodation they needed post-surgery in Perth.

These two houses named Haywood and Hutchison after two senior nephrologists are the only private, fully furnished and fully subsidised living quarters for live donors in Perth. The WA PATS or WACHS schemes cover the cost of accommodation and KHA covers utilities, cleaning and insurance ensuring a zero cost for patients and a stress free comfortable stay.

KHA has now expanded the eligibility criteria for patients to include transplant recipients and home training patients to better utilise the facilities and meet the demand of greater rural renal patients in need. Over 2013, nine separate families benefited from the two FAITH houses established in Western Australia. These families included live kidney donors and their recipients, kidney transplant recipients and a home dialysis training patient. Families came from all over the state from rural areas such as Gnowangerup, Northam, Geraldton, Northampton and Beverley.

One Deadly Step

Kidney Health Australia was delighted to support the One Deadly Step program in New South Wales for a second year during 2013. This program, run by the Chronic Care for Aboriginal People unit at the Agency for Clinical Innovation, screens for indicators of chronic disease amongst Aboriginal and Torres Strait Islander people at dedicated family-orientated events.

In 2013 the program was run in Redfern, Leeton, Narranderra, Griffith and Murrin Bridge screening members of the local community. Kidney Health Australia has contributed to this program by providing clinical guidance and consultation, the facilitation of the provision of point of care testing machines, and staff to assist in the running of these events.

KHA has now expanded the eligibility criteria for patients to include transplant recipients and home training patients to better utilise the facilities and meet the demand of greater rural renal patients in need.
Big Red Kidney Bus

Significant progress was made on the first Big Red Kidney Bus over the year. In August, Latrobe Valley Bus Lines arranged for a school bus 534 (donated by Ventura Bus Lines) to be driven to Macksville in Northern New South Wales to Carol and Paul Hoffman at Express Coach Builders and Kerry Ward at BusFurb, to commence its transformation into the Big Red Kidney Bus. The bus interior has now undergone a total refurbishment and conversion to a three-chair mobile dialysis unit. This was a key milestone in its historic journey.

While Kidney Health Australia now owns the Big Red Kidney Bus and Monash Health will be providing all medical and clinical services and staff on the bus once complete, Latrobe Valley Bus Lines is also an essential corporate partner in the project. They will be managing the drivers, servicing, maintenance and housing of the Big Red Kidney Bus at their Morwell Depot.

Kidney Health Australia was also successful in attracting funding from the John & Thirza Daley Charitable Trust, managed by Perpetual, for the services of an external, independent evaluation consultant for the first 12 months of the Big Red Kidney Bus project. This evidence will inform development of Big Red Kidney Buses in other states and territories in Australia and should streamline their development.

Once launched, the Big Red Kidney Bus will spend 6 weeks at a time at a range of Victorian holiday destinations. In an international first, all Australians on dialysis in a hospital, satellite dialysis unit or on home dialysis from all states and territories will be welcome to register for their dialysis on the Big Red Kidney Bus in Victoria.
Acknowledgements
Acknowledgements

Bequests

Estate of Hilton Bartlett
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