

Annual Report 2010/11

Kidney Health NEW ZEALAND

P r e v e n t i o n • S u p p o r t • R e s e a r c h

Kidney Health NEW ZEALAND

Prevention • Support • Research

Annual Report for the year ended 31 March 2011

Board

The full Board is as follows:

Chairman	David Henderson (Wellington)
Treasurer	Assoc. Prof. Richard Robson (Christchurch) Dr David Voss (Auckland) Mrs Nora Van der Schrieck (Auckland) Paula Daye (Auckland) - resigned May 2010 Humphry Rolleston (Christchurch) Linda Gremell (Christchurch)
Secretary/Director Medical Director	Guy Johnson (Christchurch) Prof. Kelvin Lynn (Christchurch)

Acknowledgements

Kidney Health New Zealand wishes to take this opportunity to thank the following for their generous support during the year:

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Nick Polaschek – Senior Project Manager,
Sector Capability & Innovation Directorate,
Ministry of Health
New Zealand Renal Units
Canterbury Medical Research Foundation
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Remembrance donations

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Bequests

Estate Deirdre Mary McAnulty

Donations - \$500 and over

Lendich Construction Ltd	\$1,200.00
Sanitarium Health Food Company	\$1,625.00
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Kidney Health New Zealand

2011 Chairman's report



The past 12 months have been eventful for everyone based in Christchurch – individuals, families and enterprises, whether in business, government or as public benefit organisations such as Kidney Health New Zealand.

The earthquakes have affected KHNZ, and our staff, and on behalf of the Board I warmly acknowledge the efforts of our staff to carry on despite the stresses and disruption. Much is still being achieved, carrying forward our plans based on the Vision: Better Kidney Health for All New Zealanders.

Dave Henderson, Chairman

Much more detail of the work that KHNZ has achieved in the past year is in the reports of our Medical Director Kelvin Lynn, our Education Manager Carmel Gregan-Ford, and Director Guy Johnson. Sincere thanks to them and to our Administrator Deanne Hock.

The achievements have all been within our Strategic Plan 2008-2011, as updated in September 2010, and Business Plan 2010-2011. Through these the Board has provided a framework for staff to focus their efforts. For their volunteer contributions to this, and their input and support with the week-to-week running of the organisation, I warmly thank the Board members; Treasurer Richard Robson, Nora Van der Schriek, David Voss, Linda Grennell and Humphry Rolleston.

Key Goals in our plan include dissemination of information that assists our stakeholders; kidney patients, families, staff at hospital Renal Units, GPs and staff at health services. The first series of information resources that we produced, using funds allocated for the purpose by the Ministry of Health, has been very well received and we are now working on a second series. The work is ably coordinated by Education Manager Carmel Gregan-Ford, assisted by a panel of volunteers who bring a range of perspectives. Our warm thanks to all for your commitment. The completed resources are available at www.kidneys.co.nz and www.moh.govt/nrab.

We will continue to work with the Ministry on other issues identified in our Strategic Plan and in the workshops we are holding with patient support groups around the country. Progress is being made on all of our identified priorities;

- Increasing the frequency of kidney donation,
- Improving support for living kidney donors (particularly re lost income),
- More rapid processes for renal patients who have identified a potential live donor, and
- Assistance with costs of home dialysis, in recognition of the impact on family budgets and the savings DHBs can achieve from this shift.

Other identified priorities are continuing, such as;

- Support to local patient support groups, with information and with a series of regional workshops and information days.. Patient support groups are also regular users of our information resources, either through the website or the 0800 KIDNEY (0800 543 639) information line.
- Working together with Diabetes New Zealand – we recognise that 46% of patients starting dialysis in 2008 had diabetes as the cause of their kidney failure. National President Chris Baty and CEO Joe Asghar have been supportive of joint effort.
- World Kidney Day provides a special opportunity to focus our education efforts and kidney checks were held in a range of venues. At Parliament there was a successful day of free checks for symptoms of kidney disease or diabetes, benefiting staff and MPs.

As noted a year ago, we can do little without a strong financial base. Thanks to the work of our Executive Director and Treasurer we completed the past financial year with a low and controlled level of deficit, and we are able to take steps to reduce expenditure and avoid unnecessary reduction in our assets.

In this regard, I want to particularly acknowledge and thank all those who have given support to Kidney Health New Zealand, whether in time, energy, donations large or small, or bequests. Together we are able to, and will, continue to make a meaningful difference for people with renal disease and their families in New Zealand.

Dave Henderson, Chairman

Kidney Health New Zealand

2011 Medical Director's report



The earthquakes of 4 September 2010 and 22 February 2011 and the 7000+ aftershocks have affected KHNZ and its staff as they have the rest of the Canterbury community. The staff at KHNZ and their families have all suffered significant damage to their homes.

The KHNZ premises in St Asaph Street came through the quake well. There was marvellous support from other renal units for the Christchurch dialysis patients and the local nephrology and dialysis staff. The Christchurch renal unit staff is to be congratulated on their swift and efficient response to the needs of their patients.

Kelvin Lynn

KHNZ continues to develop its links with patient support groups, Diabetes New Zealand, the Ministry of Health, Parliamentarians and the National Renal Advisory Board. Goals for KHNZ during 2010/11 have been:

- increasing kidney donation, improving support for kidney donors and streamlining kidney donor & recipient assessment
- improving information for and about people with kidney disease
- raising awareness of the need to provide assistance with the costs of home dialysis
- community education targeting groups at high risk of kidney disease
- Kidney Awareness Week and World Kidney Day activities

Chronic kidney disease (CKD) in New Zealand

The Australian and New Zealand Dialysis and Transplant Registry (www.anzdata.org.au) and the sixth annual New Zealand Dialysis and Audit report (www.moh.govt.nz/nrab) report that at the end of 2009 there were 2,260 people on dialysis and 567 started dialysis during the year (15 percent increase on the previous year with the greatest increase in the over 65 year age group). Diabetes remains the major cause of kidney failure. The incident rates for dialysis vary markedly across the country from 63 new patients per million population (pmp) in Dunedin to 224 pmp in Northland. Renal units serving populations with a high proportion of Maori and Pacific people have the highest rates of people on dialysis. New Zealand continues to be a world leader in home dialysis but there is considerable variation across the country in the rates of peritoneal or haemodialysis.

There were 1,403 people alive with a functioning kidney transplant. Unlike countries such as Australia and the USA there are no accurate figures for the number of people with advanced CKD not on dialysis or how many people die with renal failure without having dialysis treatment.

An experienced, well-trained workforce is needed to care for people with kidney disease. During the year there have been significant changes in the nephrologist workforce. Sadly, Dr Drew Henderson left his sole nephrologist post in Hawke's Bay to return to work in Scotland. During his time in Hawke's Bay he raised the profile of the needs of people with chronic kidney disease and made significant developments to local services. Taranaki now has two new nephrologists, Dr Allister Williams from the UK and Dr Ashik Hayat from Saudi Arabia. The new renal service for the Waitemata DHB, based at North

Shore Hospital, is up and running and has five nephrologists under the leadership of Dr Walter Van Der Merwe. The large Midland Regional Renal Unit based at Waikato Hospital in Hamilton, which provides end stage renal failure and dialysis services for Lakes, Bay of Plenty, Waikato and Tairawhiti DHBs, and supports two satellite dialysis units based in Tauranga and Rotorua, now has four full-time nephrologists. The Palmerston North renal unit has two permanent nephrologists. The Northland renal unit has four nephrologists and supports satellite units at Kawakawa and Kaitaia.

Working with Diabetes New Zealand

KHNZ and Diabetes New Zealand resolved to work more closely together because of the close links between diabetes and CKD. The Executive works with Diabetes New Zealand's President, Chris Baty, and Chief Executive, Joe Asghar, on shared issues of concern. This collaboration was featured in a prize-winning poster presented at the recent meeting of the International Federation of Kidney Foundations in Vancouver.

Some areas where the two organisations have combined their efforts were: a joint presentation to the National Health Board in November 2010, an invitation from Diabetes New Zealand for the Medical Director to speak on "Diabetes and Kidney Disease – the health and economic impact" to parliamentarians in May 2010 as part of their regular visits to Parliament and joining forces for community screening.

Liaison with other support groups

Patient support groups continue to provide an essential local resource for people with CKD. The Medical Director and Education Manager attended the following meetings of patient support groups in 2010 - Tauranga and Rotorua with assistance from the Auckland District Kidney Society (22 and 23 September), Nelson (4 Oct) and Invercargill (16 October).

Support for live kidney donors

Michael Woodhouse, National list MP from Dunedin, is sponsoring a bill with the intention of further reducing financial barriers to live donation of kidney or liver tissue for transplantation. The Financial Assistance For Live Organ Donors Bill would increase the support for donors from the equivalent of the sickness benefit to the equivalent of 80 per cent of the donor's pre-operation earnings – the same formula applied to income support for ACC recipients. KHNZ, the NRAB and a meeting of New Zealand nephrologists in late 2010 all support this bill.

World Kidney Day 10 March 2011

The theme for the sixth World Kidney Day was Protect your kidneys, Save your heart. World Kidney Day provided an opportunity to call the community's attention to the large, and often unappreciated, role played by CKD in increasing the risk of premature cardiovascular disease. Cardiovascular disease (heart, stroke and blood vessel disease) is the leading cause of death in New Zealand, accounting for 40% of deaths annually. Although planning for WKD 2011 was complete by mid February, the quake disrupted KHNZ staff's subsequent involvement.

We are grateful to the staff at Whangarei and Hawke's Bay who kindly agreed to proceed with the arranged events without KHNZ being present. The occupational health nurses at Griffin's in Auckland offered CKD screening to their mainly Polynesian workforces. The annual visit to the Beehive to perform kidney checks on the MPs and staff went ahead as usual with the help of the Wellington team.

Research funding

The Board resolved to provide research funding of \$57,782 for Dr Rhonda Shaw of Victoria University for her study entitled "A critical bioethics of kidney health: An ethnographic and philosophical investigation".

Other research projects currently supported by KHNZ are:

- Effect of High Muscle Mass and Body Weight on Renal Function Estimates, Assoc. Prof. Chris Florkowski (\$40,065)
- The experiences of non-directed living kidney donors, Dr Nick Cross (\$4,500)

KHNZ work with the Ministry of Health

KHNZ has been fortunate in the support it receives from the Ministry of Health for its work, in particular from Nick Polaschek, Senior Project Manager/Team Leader in the Sector Capability & Innovation Directorate.

Work, funded by the Ministry of Health, is well underway for the development of more web-based patient resources. In a project lead by Carmel Gregan-Ford a wide ranging group of stakeholders is developing three new resources related to supporting people with kidney disease - Income support, Transport and accommodation support and Dealing with loss and grief. An additional five resources on kidney disease relevant to children and their families developed with the help of Dr Tonya Kara at Starship Hospital are near completion. On completion these resources will be accessible at www.kidneys.co.nz and www.moh.govt.nz/nrab.

KHNZ continues to lobby the Ministry of Health regarding the following issues of importance to people with CKD:

- increasing financial compensation for living kidney donors
- streamlining access to assessment and surgery for kidney donors and recipients
- recognition and financial support for people on home dialysis
- improved regional co-ordination and access to renal services
- continued support for the work of the NRAB

KHNZ has obtained financial support from the Ministry for a revision and reprint of the booklet given to all patients with advanced kidney failure – "Living with Kidney Failure".

National Renal Advisory Board

Dr Mark Marshall from Middlemore Hospital took over as Chair from Dr Johan Rosman in 2010. The full board membership can be seen at www.moh.govt.nz/nrab. Confirmed public versions of the minutes are available on the NRAB and KHNZ websites. The Medical Director's position on the NRAB enables KHNZ to contribute to the development of renal services in New Zealand. Issues being addressed over the past year by the NRAB that are of interest to KHNZ are:

- A national funding model for renal transplantation
- Development of regional and national renal IT systems
- Improving the assessment process and support of living kidney donors
- Tools to support GPs looking after people with CKD
- Production of the annual national audit of dialysis treatment in New Zealand
- Training of dialysis technicians
- Support for health professional education on home dialysis

I am grateful to the board, the other members of the Executive team, my nephrology colleagues and many members of patient support groups for their support and advice over the past year.

Kelvin Lynn, Medical Director

Summer Studentship

Urinary Cystatin C and Microalbuminuria as Biomarkers of Sepsis and Acute Kidney Injury



Tom Wilkinson, winner of the award for the 'Best Presentation in the Clinical Category'.

Supervisors: Dr John Pickering, Professor Zoltan Endre and Dr Geoffrey Shaw. Sponsor: Kidney Health New Zealand

Acute kidney injury (AKI) is a common condition characterized by a rapid decrease in kidney function. In the intensive care unit (ICU), AKI affects about one in three patients and is often fatal. Early diagnosis could lead to better outcomes for patients, yet the current "gold standard" for diagnosis only picks up AKI days after it has occurred. Another important condition in the ICU is sepsis, a nasty infection that is also common, often fatal, and hard to diagnose.

The discovery of new diagnostic tests for AKI and sepsis could benefit many patients in the ICU. In this study, ICU patients with greater amounts of cystatin C or albumin in the urine were more likely to have acute kidney injury or sepsis. This information is being used to develop clinically useful tests to diagnose acute kidney injury or sepsis in severely ill patients.

While a lot more research is still required, this studentship has made one small step towards enhancing the diagnosis of AKI and sepsis and thus one small step towards improving the health of ICU patients.

Kidney Health New Zealand

2011 Education Manager's report

The past year 2010/2011 has without doubt been the most challenging year since being in this role. But as the saying goes "what doesn't kill us only makes us stronger" and as I write this I feel the future is looking brighter for those of us living and working in Christchurch. It will require commitment and a lot of hard work from all Cantabrians and the rest of New Zealand for the rebuild. We are very grateful for all the support we have had and continue to receive following the earthquake and the uncertainty it has left in its wake.

That said, Kidney Health New Zealand has managed to continue its work and is looking forward to continuing to raise its profile, and that of kidney disease in New Zealand.

The Future of Organ and Tissue Donation Conference

The Future of Organ and Tissue Donation, an interdisciplinary seminar covering a wide range of issues to do with organ and tissue donation and transplantation in New Zealand, was held at Victoria University, Wellington in April 2010. I was fortunate enough to attend and found it a fascinating day. It was interesting to hear from an anthropological perspective around the subjects of xenotransplantation, compensation for donors and the issue of commercialisation.

Kidney Health New Zealand is often approached regarding this topic so it was a valuable educational opportunity and gave an interesting perspective on the topic.

Annual Senior Renal Nurses' Conference

The annual senior renal nurses' conference was held in Auckland in September 2010, the weekend of the earthquake. Once we had established family and friends were safe we were able to enjoy another successful workshop. As usual, the presentations were of a high standard with nurses sharing their knowledge and experiences with the group.

Chris Baty, President of Diabetes NZ, gave a very interesting, if not sobering, talk highlighting the predicted rise in diabetes, particularly Type 2. Currently there are 200,000 people diagnosed with diabetes in New Zealand, although it is estimated there are at least 70,000 who are not diagnosed yet! The motto for Diabetes NZ is Diabetes: Contained, Controlled, Cured.

Rachael Walker talked about her pathway to becoming the first (and youngest) nurse practitioner in the area of renal medicine in New Zealand. It has taken years of hard work and dedication to achieve this role and, so congratulations Rachael.

Jo Burton, renal recipient transplant coordinator at Auckland Hospital, spoke about what is new in transplantation. This included ABO incompatible transplantation, the paired exchange programme and non heart beating donors.

Kidney Information Forums

These continue to be very popular. Kelvin and I have travelled to Rotorua, Tauranga (with Auckland District Kidney Society), Nelson, Invercargill and Wellington speaking to both patients and people wanting information about kidney disease and treatment and also prevention. These sessions are offered to the local groups as we feel it is a much better way to provide information and to raise awareness at the same time. We have



Chris Baty, President of Diabetes New Zealand, speaking at the Annual Renal Nurses Conference.

been pleased with the numbers attending these forums with an average of 30 - 40 people.

Having people from the local area involved has been great with local pharmacists and dietitians being able to give useful advice. They also tell us they learn a lot about kidneys disease as they research for their talks.

Further kidney forums are planned for 2011.

Web based resources

We continue to work on our website to keep it as up to date as possible. The feedback regarding the resources developed with the Ministry of Health support has been positive. It has also been very helpful to refer people to our website to check out the information appropriate to their needs. We are currently working on a second group of information brochures for the Ministry around non clinical resources and information for parents of children with kidney disease.

As part of the process I undertook a stocktake of renal patient information resources currently being used in New Zealand Units, some Australian Units, and kidney patient support groups. With this information a representative reference group was formed and during this initial meeting it became clear that the resource needed to be refined into three separate documents. Members of this group included, renal patients, pre dialysis nurses, social workers, transplant patients, and representatives from kidney patient support groups.

This work is projected to be completed by the end of 2011.

The 0800 Free Phone Information Line

The 0800 information line remains a useful resource for people, with information around kidney disease; treatment and particularly live kidney donation continuing to be the most commonly sought after topics. The number of health professionals calling has continued to increase, with a large number requesting our Chronic Kidney Disease guidelines for GPs.

Renal Society of Australasia Conference – Cairns 2010 Report

I was fortunate enough to attend the 38th National Conference of the RSA, this year held in Cairns. The theme this year was “Making Waves through Rising Tides of Innovation”. There were a large number of Keynote and Guest Speakers, with a wide variety of experience in number of different areas. These conferences are always a great opportunity to network with staff from renal units from Australia and New Zealand, and are invaluable to keeping up to date.

We heard from Kidney Health Australia (KHA) of their experience of building a consumer driven support group through organisational partnership and consumer education. They talked about the patient forums held throughout the various states. These were run by KHA and held in places such as the local bowling club, to make them less formal and encourage more people to attend.

Patients and their caregivers/family were invited to attend via advertisements in their local renal units and clinics. The forums were patient driven and included talks on a variety of topics including medication management, transplantation and support services. Prizes were given out as an incentive for completing evaluation forms at the end of the sessions, participants were also asked to identify whether they were a patient, a carer or family member. The results were collated for future forums. It was good to know that Kidney Health New Zealand has already commenced a similar initiative which has had positive feedback.

Kidney Health Week, incorporating National Drink Water Week and World Kidney Day 2011

Although the earthquake was forefront in everybody’s mind, we decided it was important to continue, where we could, with plans already in place for the week in other parts of the country. I can’t thank the renal unit staff from around the country enough for flying the flag in our absence.

The theme for this year was **Protect your kidneys, save your heart.** Running from Monday 7th through until Sunday 13th March 2011, this annual event provides an opportunity for us to raise awareness about kidney disease and its impact on New Zealanders.

The week, which includes World Kidney Day, enables us to provide a visible opportunity to inform and educate health policy-makers, people who are at highest risk of CKD, and the general public that kidney disease is common, harmful and treatable.

There was also a strong emphasis on diabetes, which is the leading cause of chronic kidney disease. Hypertension, obesity and smoking are also major causes of kidney damage. As we all know lifestyle changes over the past decades have lead to an increase in diabetes and cardiovascular diseases. Too many people still ignore the conditions that have generated the significant public health problem of kidney disease and more people need to be made aware of this.

Although it has been an unsettling year for our organisation, we look forward to continuing our work and I am excited about our future as we work to increase awareness of kidney disease and work towards providing education and support about the impact and treatment in New Zealand.

Carmel Gregan-Ford, Education Manager

Up close and personal with Dr Rhonda Shaw A KHNZ funded research project



My job: Sociologist

For the last eight years I have been working as a sociologist at the School of Social and Cultural Studies, Victoria University of Wellington. My job involves teaching Sociology to undergraduate and graduate level students, and thesis supervision. Much of my teaching is research-led and is based around the work I have been doing since 2002 on tissue exchange and the relation between sociology and bioethics.

So far, the tissue exchange work has entailed talking to New Zealanders about shared breastfeeding (cross-nursing, wet-nursing, and human milk banking), assisted human reproduction (specifically ovarian egg donation and surrogate pregnancy arrangements), and organ donation and transplantation. I am currently engaged in a large-scale project researching New Zealanders’ experiences and perceptions of organ transfer processes, for which I initially received Marsden funding in 2007. The most recent iteration of this project entails a Kidney Health NZ funded grant to research people’s views on removing disincentives for live kidney donation, and the experience and impact of dialysis treatment on patients and their families.

The work I do is philosophical, observational, and qualitative. One of the most satisfying things for me as a sociologist is having the research findings and ideas I have communicated discussed and debated by non-academics in the public arena. I will never forget my parents whooping with laughter when I told them I wanted to be a scientist and a Go-Go dancer part-time when I grew up. I like to think these two ways of engaging with the world are not incompatible.

Indeed, it’s long been argued that the Russian-born American writer Emma Goldman said of her life’s work, if she couldn’t dance to it ‘it’s not my revolution’. Sociology is a modern social science; done well, it enhances our understanding of social and cultural life for the purpose of promoting human flourishing and wellbeing.

Rhonda Shaw

Kidney Health NEW ZEALAND

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Treasurer's report 2011

2010 was a difficult year financially for KHNZ. The loss of our major sponsor, Just Water, a lower than average level of bequests received and a slowing up of the investment market meant a drop in income of \$41,000 on the previous year.

The Board made the decision that they should continue to fund their objectives, which included research, education and society support at a high level which resulted in a deficit of \$129,000 for the year.

A full set of audited accounts are available from the Secretary Kidney Health New Zealand, 230 Antigua Street, Christchurch.

Association with Just Water ends

The long and fruitful association with Just Water will end this year. KHNZ is grateful for the significant financial support received from Just Water over several years.



Yes I want to help

Yes, I want to help in the fight against kidney disease and support Kidney Health New Zealand

\$100 \$50 \$20 \$10 Other \$.....
 Enclosed is a cheque payable to the Kidney Health NZ, or please charge:
 Mastercard Visa Account number:

Expiry Date: Signature:

Please indicate if you would like:

- | | |
|--|---|
| <input type="checkbox"/> A receipt for your donation | <input type="checkbox"/> More information on general kidney health. |
| <input type="checkbox"/> Information about kidney donation/transplants. | <input type="checkbox"/> To become a member of Kidney Health NZ |
| <input type="checkbox"/> Information about making a gift to Kidney Health NZ in my Will. | |

Name:

Address:

Thank you for your support.

Please return this form to: Kidney Health New Zealand, Level 1, 230 Antigua Street, Christchurch 8011