



kidney Health

NEW ZEALAND

Prevention • Support • Research

Annual Report 2009/2010

Kidney Health

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Annual Report for the year ending March 2010

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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Mary Martindale Hale

Board

Chairman	David Henderson (Wellington)
Treasurer	Assoc. Prof. Richard Robson (Christchurch) Dr David Voss (Auckland) Mrs Nora Van der Schrieck (Auckland) Sue Patience (Auckland), – resigned November 2009 Paula Daye (Auckland) Paula Martin (Wellington)
Secretary/Director	Guy Johnson (Christchurch)
Medical Director	Prof. Kelvin Lynn (Christchurch)

Bequests

Estate Thelma Wood
Estate S.E. Gimblett
Estate Claire Palmer-Jones
Estate D.L. Boulton

Donations - \$500 and over

W.G. Johnson Charitable Trust	\$6,476.71
Mighty River Power Limited	\$2,000.00
The McGhie Family Trust	\$500.00



Kidney Health New Zealand

2010 Chairman's report



Dave Henderson, Chairman

The past year has been an important one for Kidney Health New Zealand. A year ago I observed that we were growing in strength and in presence, a change closely linked with our promotion of a national approach to service improvements and support for people with renal disease and their families. Again this year we have demonstrated how much is possible with the right mix of leadership, information, skills and encouragement. I am proud of the leadership role Kidney Health New Zealand has taken, and the achievements that have come from that. All our Board members have been part of this achievement;

Treasurer Richard Robson, Nora Van der Schrieck and David Voss.

Subsequent to the reporting year we have regretfully accepted the resignation of Paula Daye, who needed to take time to support an ill family member. We hugely value the contribution Paula was able to make during her time on the board, to our Strategic Plan, our Business planning, and our Board Charter. We also with regret accepted the resignation of Paula Martin, who brought a valuable new perspective to board discussions but had many other pressing commitments. We wish both well, and look forward to working together more as the opportunity arises.

The Board have identified priority areas where we want to improve representation, and the highest priority is of course Tangata Whenua. Our Medical Director identifies in his report there are likely to be 12-13,000 people in New Zealand with kidney function less than a third of normal, and 31% of the people starting dialysis in 2008 were Maori, who make up just 15% of the population.

The comparable figure for Pacific people is 17% of those starting dialysis, (6% of the population) and we have begun discussion on identifying appropriate Pacific representation. The other priority area is linking with the Business community, and progress is being made there also.

Of course volunteer board members can achieve little without staff, and the day-to-day work that is behind our achievements is down to our Executive Officer Guy Johnson, Medical Director Kelvin Lynn, Education Manager Carmel Gregan-Ford, all assisted by Deanne Hock.

There are several points regarding our year that I would like to highlight.

- Our Strategic Plan 2008-2011 and our ongoing Business planning are enabling us to move ahead with clarity about our priorities and an understanding of how our overall goals guide and frame our activities.

- Little is possible without a financial base. Thanks to the work of our Treasurer and Executive Director we have come through the downturn and collapse of many financial institutions relatively unscathed, achieving a small surplus this year.
- Together with our Medical Director I have met during the year with officials of the Ministry of Health, and I particularly acknowledge the work of Nick Polaschek, Senior Manager in Sector Capability and Innovation. Our work with the Ministry has led to creation of the patient information resources that are now available online.
- We will continue to work with the Ministry on issues identified in our Strategic Plan and in the workshops we are holding with patient support groups around the country.
- Key priorities include 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.
- The Medical Director is our representative on the National Renal Advisory Board (NRAB) and many of the issues we identify are able to be moved forward in that forum, which is actively supported by the Ministry.
- We also supported appointment of a patient representative, Michael Papesch, to NRAB where he is now making his own significant contribution. We continue to support Michael with information that can assist him in the role.
- We continue to support local patient support groups, particularly with information but also with a series

of regional workshops and information days. These have met a very positive response with some great issues raised and discussed, that we have been able to feed in to the Ministry and the NRAB. Patient support groups are also regular users of our information resources, either through the website or the 0800 KIDNEY (0800 543 639) information line.

- Another priority in or plan is 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 – and National president Chris Baty has been supportive of joint effort.
- World Kidney Day provided a special opportunity to focus our education efforts, sometimes in partnership with Diabetes New Zealand. Workshops

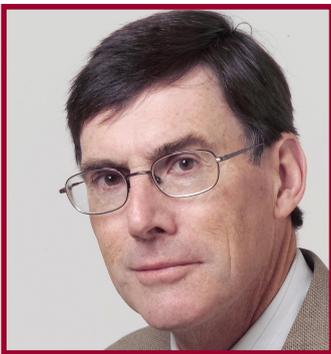
and kidney checks were held in Auckland with the Pasifika and Polyfest festivals, in Porirua at Pacific Health Services, and at Parliament there was a successful day of free checks for symptoms of kidney disease or diabetes, benefiting staff and MPs.

More detail of all these activities is in the reports of our staff, and I would like to express the great appreciation the Board have for their efforts and achievements.

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

Kidney Health New Zealand

2010 Medical Director's report



Kelvin Lynn, Medical Director

Kidney Health New Zealand (KHNZ) continues to punch above its weight. Despite the economic recession, its small executive team, with support from the Board, has actively pursued the goals set out in the Strategic Plan 2008-2011. Links with Diabetes New Zealand, the Ministry of Health, Parliamentarians and the National Renal Advisory Board have been strengthened and our Education Manager, Carmel Gregan-Ford has a full programme responding to requests to talk to lay and professional groups.

Chronic kidney disease (CKD) in New Zealand

The invaluable annual report from the Australian and New Zealand Dialysis and Transplant Registry (www.anzdata.org.au) and the New Zealand Dialysis and Audit report (www.moh.govt.nz/nrab) report that 492 people started dialysis in 2008 (6 percent increase on the previous year) and that 224 (46 percent) had diabetes as the cause of their CKD. Of those starting dialysis, 151 (31 percent) were Maori and 84 (17 percent) Pacific people. These statistics underline the increased burden of CKD borne by these groups when one considers that Maori make up 15 percent of the general population and Pacific people six percent. In 2008, the largest adult kidney unit cared for 502 dialysis patients and the smallest 60 dialysis patients. There were 1,351 people with a functioning kidney transplant. There are no accurate figures for the number of people with advanced CKD not on dialysis. KHNZ estimate that there are likely to be 12-13,000 people with kidney function less than a third of normal. The

staff and resources to treat these patients are not the same throughout the country with some renal units relatively well staffed while others are critically short of medical, nursing and allied health staff. The regional approaches to planning renal services supported by the Ministry in the Central and Midland regions provide an opportunity to address these discrepancies and are welcomed.

World Kidney Day 11 March 2010

The annual Kidney Health Week and World Kidney Day provide an excellent opportunity for KHNZ to increase community awareness regarding CKD. This year the theme for World Kidney Day was diabetes and chronic kidney disease (CKD).

Carmel Gregan-Ford describes Kidney Week's activities in more detail elsewhere in this report. Once again, I would like to acknowledge the great support received from patient support groups and renal units for the week's activities.

Research

Research projects currently supported by KHNZ are:

- *The Pivotal role of cAMP in Renal Tubular Injury*, Professor Rob Walker (\$32,035)
- *Effect of High Muscle Mass and Body Weight on Real Function Estimates*, Assoc. Prof. Chris Florkowski (\$40,065)

Summer Studentship University of Otago, Christchurch

As a result of discussions between KHNZ and local Maori health researchers, a Summer Studentship entitled *Exploring the experiences of Maori patients and whanau living with chronic kidney disease (CKD) within the Canterbury District Health Board region (CDHB)* was included in the University of Otago, Christchurch programme for 09/10. The Rapaki Branch of the Maori Women's Welfare League sponsored this project and John Armstrong, a Maori medical student, carried out the work under the supervision of Mrs Tania Huria and Dr Suzanne Pitama from the University of Otago and myself. The study explored the experiences of Maori CKD patients and their whanau living with CKD to capture their perspectives on living with CKD and its impact on their quality of life and Maori patients' perspectives on their healthcare and their interaction with the health care system. The recommendations from the study findings were that:

- Clinicians identify and recognise economic barriers and whanau roles/responsibilities when working alongside Maori patients, and ensure that management programmes are inclusive of patient realities to promote the full patient participation.
- More is done to ensure adequate and universal screening for diabetes and CKD within primary care for Maori patients to attempt to identify these problems earlier.
- More effective means of engaging with and enhancing the education of Maori patients with CKD and diabetes in the early stages of their disease are needed.
- Patients and whanau need help to understand the progressive nature of the disease and how whanau should be prepared for their support role.

Further research is required with a larger cohort of patients to explore the themes identified.

John Armstrong with sponsors from the Rapaki Branch of the Maori Women's Welfare League

KHNZ funded a study entitled *The contribution of endothelial damage and oxidative stress to kidney injury in diabetes* carried out by Helen Abbot under the supervision of Professors Tony Kettle and Zoltan Endré.

KHNZ work with the Ministry of Health and National Renal Advisory Board

KHNZ has been fortunate in the support it receives from the Ministry of Health, in particular from the retiring Director-General of Health, Stephen McKernan. KHNZ wishes Stephen well for the future. The Medical Director is a member *ex officio* of the National Renal Advisory Board (NRAB). The NRAB, with the highly professional support of Nick Polaschek, Senior Project Manager in the Sector Capability & Innovation Directorate, has now developed into a credible advisory group for health professionals, District Health Boards and the Ministry of Health. The NRAB website is worth a visit.

Kidney Health New Zealand, funded by the Ministry of Health, has developed seven web-based patient information resources. The form and content of these resources were finalized after review by a consultation group of stakeholders including health professionals and consumers. Information on these resources has been sent to all general practices. People seeking information on kidney disease and its treatment can access this on-line on the Kidney Health New Zealand (www.kidneys.co.nz), and Ministry of Health (www.moh.govt.nz/nrab) websites. Users can read the information on-line or print the documents for further distribution. Kidney Health New Zealand expects that this resource will complement the information provided to patients with CKD by their health professionals.

KHNZ continues to lobby the Ministry of Health regarding issues of importance to people with CKD: an increase in the 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.

Liaison with other support groups

Patient support groups continue to provide an essential local resource for people with CKD. After consideration of the benefits for these groups of an annual national meeting, KHNZ decided not to have a national meeting

in 2009 but rather to support local workshops with the programme determined by the local group. Successful workshops were held in Wellington on 3 October 2009 and Ashburton on 14 October 2009. KHNZ continue to work with Diabetes New Zealand, and the Diabetes Societies in Christchurch and Auckland. World Kidney Day 2010 enabled KHNZ Diabetes New Zealand to work together with diabetes health professionals to stress to the community the links between diabetes and CKD.

Kidney Health New Zealand 2010 Education Manager's report

The past year 2009/2010 has again been a busy one. A number of speaking engagements have kept me busy, travelling around the country. Any opportunity to raise awareness about kidney disease and its impact not just on the individual, but their extended family and community, is always a very worthwhile and enjoyable part of my role.

It has been very encouraging to be working more closely with Diabetes NZ. I had an article published in their Dialog magazine and we have good communication with the National President, Chris Baty. I have also spoken to several diabetes support groups during the year as the theme for World Kidney Day was Diabetes and Kidney Disease; these meetings provided a great opportunity to strengthen our links with such groups who shares many of the same challenges as we do.

Kidney Support Group Forums

Following feedback from a questionnaire sent to all support groups, it was decided that a 'road show' type format would be a better way to provide education, information and promote discussion. The forums will be held around the country enabling more members from each group to attend, as mentioned in the Medical Director's report. Another four forums in other parts of New Zealand are booked for 2010.

Kidney Health Week, National Just Water Week and World Kidney Day

The theme for World Kidney Day 2010 was Diabetes and Kidney Disease. In Porirua I spoke to the Oratoa Health Unit's diabetes group about the risk of kidney disease for people with diabetes and what they can do to help reduce the risk.

On Thursday 11th March, we were in Porirua working with the Pacific Health Service and the local PHO



MP Tau Henare takes note of his BP taken by Miranda Walker during the annual KHNZ visit to Parliament March 2010.

performing kidney checks, i.e. blood pressures and urine tests for protein. The Diabetes Nurse Specialist from the Capital and Coast DHB worked alongside us and, as usual, the team from the Wellington Renal Unit was a great help. The day generated some media interest with photos in the local paper.

On Saturday 13th March, I manned a site at Pasifika together with staff from the Auckland DHB renal service. We were kept busy with blood pressure checks and a number of people were found to have high blood pressure and GP follow up was advised.

On Tuesday 16th March, we were at the Beehive performing our annual kidney checks on the MPs and staff. Correspondence was sent to each MP, including some words from Diabetes NZ, prior to our arrival. It was noted that a prominent Member of Parliament recorded a very high blood pressure during our visit,

much to his surprise. He has since been diagnosed with Type 2 Diabetes. We like to think our visit was a catalyst to his getting checked!

Staff from Counties Manukau DHB attended Polyfest in South Auckland. The four days that this event ran were attended in the main by students from schools throughout Auckland and surrounding areas. Our attendance was again about making sure we are getting our message out to those most at risk.

The Wellington Region Kidney Society put our WKD posters up in trains around the city and handed out brochures in the busy downtown area. Staff and renal patients were out in force in a busy shopping mall in Dunedin taking blood pressures and giving out information; even appearing on local television.

All staff carrying out the kidney checks were wearing WKD tee shirts and handing out stickers and brochures. Some of the kidney patient support groups around the country put up posters and displays in their local areas to help promote the week.

Once again we could not have achieved any of this without the tremendous support of the staff and support groups from these areas and are very grateful for their enthusiasm and support.

Senior Renal Nurses Conference

In September we held our annual senior renal nurses conference in Auckland. This always proves to be a very popular event with more requests to attend than spaces available. This year was no exception with the feedback being very positive. We were fortunate enough to have some excellent guest speakers as well as a high standard of presentations from the renal nurses. Nick Polaschek, Senior Renal Project Manager for the Ministry of Health, spoke about the nursing and renal service improvement project work in New Zealand, focusing on the current work being done by the Ministry with the national renal project. Dawn Kelly, Project Manager from the Central Regional Renal Network, spoke about the work being done following a review of renal services. Judith Dee, Diabetes Nurse Specialist from Counties Manukau DHB, talked about the burden of diabetes. Needless to say, as is always the case, there was plenty of networking and sharing of ideas.

Pasifika 2010 where KHNZ had a stand. Emma Marsh takes a visitor's blood pressure.

0800 Information Line and Website

The 0800 free phone line has become increasingly busy during the last month, with many requests from people wanting to visit New Zealand but requiring dialysis while they are here. Unfortunately, this is not always achievable with the resources already stretched in many of the country's dialysis units. There has also been an increase in the number of people requesting information about live kidney donation.

Our medical director, Kelvin Lynn, has now taken up residence in our office, one day a week, having retired from the nephrology department at Christchurch Hospital, after 30 years service. We meet weekly to plan and discuss any current initiatives and issues.

We continue to keep our website updated and have recently added the new patient information resources that we completed for the Ministry of Health and which Kelvin has described in his report. The website receives positive feedback regarding the information provided and ease of use. We have made some changes to ensure ease of access for people searching for kidney related information and welcome feedback that enables us to improve this service.

As usual there have been a number of speaking engagements and screening opportunities throughout the year. Included were a visit to Canterbury Meat Packers, who employ over 600 staff, where we provided education and kidney checks for staff, and talks to service groups, students and other health groups. Once again, it is always wonderful to have the opportunity to raise awareness about kidney disease in the wider community and continue our message about the importance of early detection and intervention.



Treasurer's Report

Kidney Health NZ achieved several important milestones in terms of its business and strategic plans this year despite income being down by 30% on the 2009 year. Prudent control of expenses and an impairment provision recovery on investments resulted in a \$70k surplus for the year. Research and Education, our core values, continue to be funded at the highest possible level. A Ministry of Health contract provided a new source of income during the year and future contracts with them should expand our income stream during these difficult times.

	2009	2010
Income	468,680	324,765
Total Expenses	775,028	255,356
Surplus (deficit)	(306,348)	69,409
Equities	1,320,519	1,389,926

A full set of audited accounts are available from the Secretary, Kidney Health NZ, 24 St Asaph Street, Christchurch

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:

- A receipt for your donation
 More information on general kidney health.
- Information about kidney donation/transplants.
 To become a member of Kidney Health NZ
- 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, 24 St Asaph Street, Christchurch 8011