



kidney Health

NEW ZEALAND

Prevention • Support • Research

Annual Report 2008/2009

Annual Report for the year ending March 2009

Acknowledgements

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

- Just Water (Red Eagle Corporation)
- Community Publishing Company Limited
- Roche Products (New Zealand) Limited
- Ocean Spray
- Nick Polaschek - Senior Project Manager, Sector Capability & Innovation Directorate, Ministry of Health
- New Zealand Renal Units

Board

Chairman	David Henderson (Wellington)
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Donations - \$500 and over

Noel & Melva Charitable Trust	\$2,000
Tui Gaspard	\$2,000
Sarah Chapman (Fundraise OnLine)	\$1,671.10
W.G. Johnston Charitable Trust	\$5,139.81
NZ Kidney Research Trust	\$4,873.34



Kidney Health New Zealand

2009 Chairman's report



Dave Henderson, chairman

Kidney Health New Zealand is the leading national organisation in this particular area. Our focus, as our letterhead indicates, is Prevention, Support and Research, and our Board involves patients, physicians, kidney donors, family members, and support workers.

We work together based on a shared vision of what can be achieved, and in this we are part of Hawken's social movement that spreads through every city in every country, involving nearly every tribe, culture, language and religion, providing support and meaning to billions of people.

Hawken describes the three basic roots of this movement: environmental activism, social justice and indigenous cultures' resistance to globalism – all of which have become entwined as an expression of the desire of the majority of people on this earth to sustain the environment, wage peace, democratise decision making and policy, and reinvent public governance.

The Strategic Plan developed by the KHNZ Board can be seen as an expression of the particular needs of renal patients and families in relation to these themes. The plan is broad, so it has provided the basis for a wide range of actions, but they all address our core focus.

Details of our work are in the following reports from our Medical Director Kelvin Lynn and Education Officer Carmel Gregan-Ford. I want to express my thanks and that of the Board for their commitment, dedication and efforts on behalf of KHNZ. Particularly pleasing are the positive and productive relationships we have been

In 2008 Paul Hawken published the book "Blessed Unrest: How the greatest movement in the world came into being and why no one saw it coming". This book has been described as the real news of our time – a manifesto of hope, and Hawken concludes that this is the largest social movement in history.

In the book Hawken describes this as a movement of individuals who may never meet or know each other, but who are part of a coalescence made up of hundreds of thousands of organisations.

Kidney Health New Zealand is one of these. We have grown as a result of our shared recognition that we can improve services and support for people with renal disease and their families in Aotearoa/New Zealand.

able to build with the Ministry of Health and with regional and local patient support societies.

I would also express my thanks to all the other Board Members, and to our Executive Director Guy Johnson. I have appreciated your commitment to the vision of KHNZ, and your patience while I work through a difficult time with my own kidney failure, dialysis and transplantation. I look forward to continuing to work together as a Board, building on our achievements to date and supporting continued improvement in the services and support available to renal patients and their families.

FINANCIAL POSITION

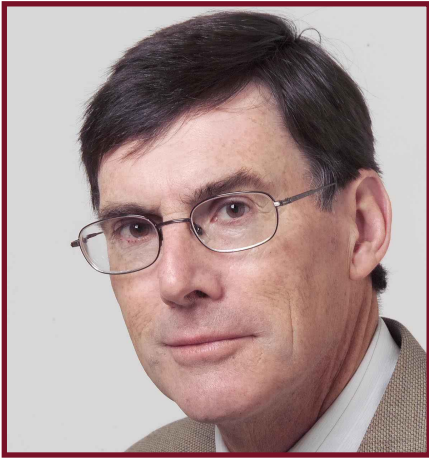
The year to 31 March 2009 saw an increase in income over the previous year by \$115,000. The increase is due to bequests totalling \$200,000.

Whilst expenses were down on the previous year by \$44,000 the downturn in the financial sector meant that we have an impairment in our investments of \$333,000. Unfortunately, one of these investments might not be recoverable. This has reduced the Trust's equity as at 31/3/2009 to \$1,317,790 down from year end 2008 \$1,626,867.

Full audited financial statements are available from Kidney Health New Zealand, 24 St Asaph Street, Christchurch.

Kidney Health New Zealand

2009 Medical Director's report



Kelvin Lynn, Medical Director

Introduction

It has been three years since I became the Medical Director of Kidney Health New Zealand (KHNZ). During this time, the organisation has changed significantly. There has been a change of name and a consolidation of links with kidney units, patient support groups and the National Renal Advisory Board (NRAB). Kidney Health New Zealand now has a national presence as evidenced by our being awarded a contract by the Ministry of Health to produce web-based information resources and the Medical Director being an *ex officio* member of the key national advisory group on renal services, the NRAB. Working for KHNZ has been enjoyable and I have had great support from my colleagues in the Executive – Guy Johnson and Carmel Gregan-Ford. Our Chairman, Dave Henderson, provides wise guidance for the organisation and much appreciated support for the Executive.

The Executive have been working hard over the past year to achieve the goals set out by the Board in the Strategic Plan 2008-2011.

Chronic kidney disease in New Zealand

The invaluable annual report from the Australian and New Zealand Dialysis and Transplant Registry shows that 461 people started dialysis in 2007 and that 41 percent had diabetes as the cause of their kidney disease. At the end of 2007, there were 2,064 New Zealanders on dialysis: 30 percent hospital dialysis, 19 percent satellite dialysis, 51 percent home dialysis. The largest adult kidney unit had 444 dialysis patients and the smallest 59 dialysis patients. There were 1,289 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.

New Zealand leads the world in the provision of home dialysis but there has been decline in the proportion on home haemodialysis or peritoneal dialysis and an increase in hospital and satellite dialysis. It is pleasing to hear of the success of the recently opened home training unit at Auckland Hospital and the plans to develop kidney services for the half a million people living in Waitemata District Health Board region. The arrival of Dr Drew Henderson in the Hawkes Bay has enabled that region to develop its own services after years of support from Wellington. The kidney unit at Waikato Hospital responsible for the large Midland

region is under great pressure because of difficulties in attracting and retaining sufficient kidney specialists. Living donor transplants continue to increase in number and new transplant technologies – paired kidney exchange and ABO incompatible transplants (only in Auckland) – are now available. The Health Select Committee recently addressed the issue of organ donation and the need for an organ donor registry. KHNZ's position is that establishing and maintaining such a register would be complicated, expensive, and unlikely to increase organ donor rates. It is pleasing to note that a report to the Committee from Margie Apa, Deputy Director-General, Sector Capability and Innovation, at the Ministry of Health supported this view.

A major achievement this year has been the development of a simple guide for family practices on the management of CKD. Royal New Zealand College of General Practice, the Ministry of Health and renal units, supports this CKD Treatment Guide. Copies were delivered to 3,800 GPs in April with the assistance of the College. The University of Otago has ordered 350 copies for medical students and a number of professional groups have asked for additional copies.

World Kidney Day 12 March 2009

A major focus each year is the annual Kidney Health Week and World Kidney Day. The International Federation of Kidney Foundations (IFKF) and the International Society of Nephrology share the global management of World Kidney Day. These events during

the week of 9 – 15 March 2009 provided an ideal opportunity for KHNZ to deliver its message to the public and politicians and to raise its profile. This year the theme for World Kidney Day was the link between high blood pressure and chronic kidney disease (CKD). Carmel Gregan-Ford describes Kidney Week's activities in more detail elsewhere in this report. I would like to acknowledge the great support received from patient support groups and renal units for the week's activities. The theme for World Kidney Day 2010 will be "CKD and Diabetes".

The increasing public profile of KHNZ has led to large organisations and service groups requesting CKD screening. Currently such screening – blood pressure measurements and urine protein tests - has been provided by KHNZ staff and local nurse volunteers. All those screened receive written advice on the results of screening and any need for follow-up in primary care. The results of screening done to date suggest that the estimate of one in ten adults having a sign of CKD is likely to be accurate.

Research

Funding of research has been a key activity of KHNZ since its inception. The Strategic Plan identifies specific research areas that KHNZ would like to fund. In 2008, no research applications met these criteria. Six research grant applications received this year are under review by the Scientific Assessment Committee of the Canterbury Medical Research Foundation. The Board will make the final decision on funding after receipt of the committee's report in mid August. KHNZ funded a Summer Studentship at the University of Otago, Christchurch for 10 weeks over the university vacation for a medical student, Isaac Campbell. Dr John Pickering from the Christchurch Kidney Research Group supervised Isaac's project *Timing of injury and biomarker-based diagnosis of Acute Kidney Injury (AKI)*. Isaac won the prize for the best scientific report.

Research projects currently supported by KHNZ are:

1. *Kidney Disease and Quality of Life Follow-up Study*, Dr Sarah Derrett (\$32,280)
2. *Characterisation of genes involved in polycystic kidney disease in a sheep model*, Professor Michael Eccles (\$35,817)
3. *Renal Endothelial Function in Models of Chronic Renal Failure*. Professor Zoltan Endre (\$76,668)
4. Lyn Lloyd, Senior Renal Dietitian at Auckland City Hospital, received \$3,000 to attend the

International Congress on Nutrition and Metabolism in Renal Disease in Marseilles, France. Lyn's comprehensive report from this meeting is available from the KHNZ office on request.

KHNZ work with the Ministry of Health

KHNZ is fortunate in having excellent support for our activities from Stephen McKernan, Director-General of Health and his staff at the Ministry of Health. KHNZ is particularly grateful to Nick Polaschek, Senior Project Manager in the Sector Capability & Innovation Directorate. Nick has been working with the NRAB on the Renal Service Improvement Project.

This work has five defined projects with timelines for delivery of outcomes agreed by NRAB. They are:

1. Improving CKD management in primary care
2. Increasing rates of renal transplantation
3. Regional coordination in planning to address demand and access
4. National coordination in renal workforce development
5. Improving information about and for renal patients (this work has been contracted to KHNZ)

KHNZ has a contract with the Ministry to conduct a stock take of all renal information resources and to develop five or six renal client information documents for web publication.

Issues of importance to people with CKD raised with the Ministry of Health and the Minister of Health are: 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.

KHNZ and global connections

KHNZ is a member of The International Federation of Kidney Foundations (www.ifkf.net). The IFKF's mission is "to foster international collaboration and exchange of ideas between local kidney foundations and not for profit organisations to enable and help empower local membership organisations to improve health, well being and the quality of life of all individuals at threat from kidney disease." The IFKF aims to bring a global focus to the prevention and treatment of kidney disease and has 66 member organisations representing 42 countries.

Kidney Health Australia is an active member of the IFKF and provides invaluable support to its smaller cross-Tasman cousin. The IFKF co-sponsors the World Kidney Day and is working with governments and their agencies worldwide to raise awareness of the importance of CKD as a major public health problem. I have attended the last three conferences organised by the IFKF. This has given me an insight into the problem of CKD in countries as disparate as Bulgaria and Pakistan and the responses of local kidney foundations.

Liaison with other support groups

I write a regular newsletter for the Christchurch Kidney Society that is then distributed to all patient support groups. The Executive continue to work with Elizabeth Cunningham, Ngai Tahu, member of Canterbury DHB Research Manager, Maori at the University of Otago, Christchurch to learn how best to get the message regarding CKD heard in Maori communities. KHNZ has strong links with Diabetes New Zealand, and the Diabetes Societies in Christchurch and Auckland. World Kidney Day 2009 enabled KHNZ to stress the links between hypertension and CKD.

Kidney Health New Zealand 2009 Education Manager's report



From left to right: Kelvin Lynn, KHNZ Medical Director, Carmel Gregan-Ford, KHNZ Education Manager, Jo Goodhew, MP, Kay McLaughlin, Pre dialysis Nurse, Capital Coast District Health Board, standing at the kidney screening stand inside the Beehive in Wellington.

2009 Education Manager's Report

The past year, 2008/2009, has been a busy and exciting one for our organisation, with a wide variety of activities undertaken and requests including several speaking engagements and provision of resources for a number of groups.

Kidney Patient Support Group Conference – Hamilton, June 2009

Our annual conference was held in the Waikato region, which has one of the highest incidences of kidney disease in New Zealand, and we hoped to attract some interest from the community to attend the information morning held on the Saturday.

A representative from each support group gave a brief overview of their group's activities and achievements throughout the year. I am always impressed by the dedication of these groups, nearly all run by volunteers and this year was no exception. It was also interesting to hear about the different projects individual groups focused on, including fundraising events and information sessions to support people and their families with kidney disease.

As usual at our annual conference, we opened the programme up to the general public. Advertisements were placed in the renal clinics and the local newspaper. We were pleased to see some new faces attending from the Waikato region.

Senior Renal Nurses' Conference

Our annual Senior Renal Nurses' Conference was held in Auckland in September. This conference is held specifically for nurses working within hospital renal units and satellite dialysis units throughout the country to provide an opportunity for networking and sharing ideas and initiatives around care of the renal patient. The senior renal nurse advisory group meet prior to the conference and provide a report at conference about the progress they have made in the area of education for nurses and attracting and retaining nursing staff in renal medicine.

Organ Donation Forum - Timaru

In October I spoke to Year 11 and 12 students (15 – 16 yr olds) from secondary schools in South Canterbury about Organ Donation. This was a prelude to the Organ Donation Forum held in Timaru on October 30th. It

was interesting to hear the students' thoughts around organ donation and the knowledge they had regarding this subject.

Kelvin Lynn, Richard Robson and I were invited speakers at the forum which saw approximately 150 people attending to learn more about organ donation. Two donor families spoke of their decision to donate kidneys or corneas to their loved ones: a very moving experience. A man who had a corneal transplant and a man, who had a lung transplant, spoke of their life changing experiences and their gratitude to the donors and their families. The feedback from this event was very positive.

Kidney Health Week and World Kidney Day.

World Kidney Day, marked this year on Thursday, March 12, is a major part of Kidney Health Week. The aim of World Kidney Day is to raise awareness about the role of the kidney in health and the need for early screening for people at increased risk of kidney disease. The theme for 2009 was "Keep the pressure down" to highlight the role of blood pressure as one of the key symptoms and causes of chronic kidney disease.

Lion Nathan, a national organisation with sites in all the main cities, including three in Auckland, allowed us to come into their facilities during Kidney Health Week and educate their staff and offer screening for signs of kidney disease.

Staff had their blood pressure taken and urine tested for signs of protein. Each staff member was given written information about kidney disease and the opportunity to speak to a nephrologist and/or renal dietitian (at the Grafton and Khyber Pass sites).

This screening was only possible because of the support from the nursing and medical staff from the renal units in the cities we visited. We referred 12.5% of the staff with indicators of CKD (i.e. staff with high blood pressure and /or protein in their urine) to their GPs for further investigation. Although this appears to be a large proportion it is in keeping with international experience. It is encouraging to know early detection of CKD offers the chance for early, effective treatment in many people.

Our, now annual, visit to Parliament was another successful event, with a very busy day spent screening MPs and Parliamentary staff for signs of CKD. Once again the enthusiastic team from the Wellington Hospital Renal Department made it a very worthwhile day with their assistance. Those working in the Beehive are no less at risk of CKD: 12% of the staff screened were

advised to see their GP for further investigations. Many of the staff had come back to see us following our visit last year and were keen to know if their results had improved.

Once again, the success of this week could not have happened without the help and support of the staff from the Auckland, Middlemore, Wellington, Christchurch and Dunedin renal units. We are very grateful for all of their efforts.

National Just Water Week again focused on education about kidney health and the benefits of drinking water when thirsty, rather than sugar-containing drinks, in order to prevent obesity and diabetes (the leading cause of CKD). This year there was a large increase in the number of schools wanting our resource packs to assist their schools in promoting water as the drink of choice.

Website and 0800 information line

The free phone information line continues to be well utilised with on average of 50-60 calls per month. The most common calls continue to be from people wanting information about being a live kidney donor, but I have noticed a significant increase in calls from GPs and practice nurses wanting to use our resources, which is very encouraging. Also of interest are the calls from people wanting to know how to look after their kidneys.

Our website is continually being updated; we frequently receive positive feedback about the site and the layout. With information being made available for medical professionals and patients this has been a useful tool to help provide information and resources for a wide audience, with plans to expand on the information currently available.

As a member of the Executive team for Kidney Health New Zealand, we meet weekly to ensure we are up to date with news and events happening around the country and overseas.

Throughout the year I am asked to speak to a variety of groups about various aspects of kidney health and kidney disease; groups include Rotary, Kiwanis, Women's Institutes, Catholic Women's League, Primary and Secondary Schools, Diabetes Support groups and nursing education programmes. Any opportunity to raise awareness about kidney disease and its impact, and promote detection and early intervention, is another chance to get our message out there:

"Kidney Disease is common, harmful, treatable"

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
- Information about making a gift to Kidney Health NZ in my Will.
- Information about kidney donation/transplants.
- More information on general kidney health.
- To become a member of Kidney Health NZ

Name:

Address:

.....

Thank you for your support.

Please return this form to:

Kidney Health New Zealand, 24 St Asaph Street, Christchurch 8011