

ki^oney Health

NEW ZEALAND



Annual Report 2013/14

Board

The full Board is as follows:

Chairman	David Henderson (Wellington)
Treasurer	Assoc. Prof. Richard Robson (Christchurch)
	Michael Papesch (Wellington)
	Nora Van der Schrieck (Auckland)
	Humphry Rolleston (Christchurch)
	Linda Grennell (Christchurch)
Secretary/Director	Guy Johnson (Christchurch)
Medical Director	Prof. Kelvin Lynn (Christchurch)
Education Manager	Carmel Gregan-Ford (Christchurch)

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Charities number CC11348

Acknowledgements

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

Rachael Walker
Nick Polaschek – Senior Project Manager,
Sector Capability & Innovation Directorate,
Ministry of Health
New Zealand Renal Units

Remembrance donations

Raman Ganda	Julia Margaret Hopkins
Ian Cruden	Michael John Haddock
Mary Tong	Darrell Wayne Cassidy
Marilyn Lescher	Allan Wong
Leonie Blackmore	Marilyn Lescher
Brian Gill	Helen Swete
Doreen Whaley	Roberta Prasad
Jenneth Gordon	

Bequests

Estate Brian Sydney Lendrum
Estate S.E. Gimblett
Estate Doris Muriel MacGillivray
Estate Grace Isobel Karl

Donations - \$500 and over

W. G. Johnston Charitable Trust	\$5,689.80
The Tasman Charitable Trust	\$2,000.00
Zinky's Medi Spa	\$3,890.79
Bill Bolstad	\$880.00
Pub Charities	\$10,000.00

Kidney Health New Zealand

2014 Chairman's report



Dave Henderson, Chairman

This has been another eventful and productive year for KHNZ, with all the opportunities and activities that are detailed in the reports from Kelvin Lynn, our Medical Director, and Carmel Gregan-Ford our Education Officer. Huge thanks to Carmel and Kelvin, and to Guy Johnson who has the task of managing the whole operation including the finances, and coordinating Board meetings which can be difficult with a group of heavily committed people from around the country.

This year we have made good progress with our review of the Strategic Plan, focusing our goals on the issues that really matter for renal patients, families and whanau.

Given that it's an election year, we have committed to developing our Manifesto - a Blueprint for improving renal services in New Zealand. This will be distributed to political parties in advance of the September 20 election with a request that we meet and discuss the issues. We will also ask parties to include the key points of the blueprint in their policy platform as they go into the election, and subsequently as they go into coalition negotiations. We see significant gains being possible from the Blueprint, for government, for the District Health Boards, and most importantly for patients, family and whanau.

An important contribution to the Blueprint has come from the Consumer group which we established over the past year. Members come from all parts of New Zealand and from a range of situations - diagnosed, doing dialysis, having received a transplant, or supporting a family member who has kidney disease.

During the year we were also pleased to support former Board member Paula Martin in establishing a network for kidney donors. Again, this group will contribute to our understanding of the process, and help shape the policies that are reflected in the Strategic Plan and the Manifesto.

We have continued our active role in the National Renal Advisory Board, and in that environment have offered a unique perspective, based on the discussion and debate between renal physicians and service users that happens every time our board meets, plus the input from our Consumer group.

In the Education area a key focus is Kidney Awareness Week, and we have developed a very productive link with the Mad Butcher chain. Plans in place for 2014, and we plan an expanded effort in 2015.

For Research, we are planning a review of our guidelines and process for applicants to KHNZ for grants to support research. Naturally we will prioritise research that supports the goals in the KHNZ Strategic Plan, and of course we can only budget a certain amount each year, but we see this as an important avenue for developing evidence that can be used to further improve services and outcomes.

A major goal in our KHNZ Strategic Plan for several years now has been to promote an increase in kidney transplantation, in recognition that transplantation is the treatment option that gives most patients the best result. For most patients it extends life and increases the quality of life, it reduces family stress, and most appealing to Government, it costs significantly less in the long term than other options. This theme remains in the Plan and will be a key theme in the Manifesto.

We thank the Ministry of Health for their ongoing assistance with the development of our information resources, and also the special people who have made themselves available to help make sure the information is as helpful as possible. More detail on all these projects is in the reports from Carmel and Kelvin.

I particularly want to thank the members of the KHNZ Board who have contributed through the past year, with their input on the policies and plans we have created. I particularly want to thank Linda Grennell, who stepped down from the Board this year. It has been great working with Linda, and she brought a special contribution to our discussions - Kia piki te ora, e hoa.

Thanks also to the members of the regional patient support groups who have given us their perspective on the issues that affect them. It is your input that gives our national voice its power, and we look forward to continuing this work together.

Dave Henderson – *Chairman*

Kidney Health New Zealand

2014 Medical Director's report



This report will be my last for KHNZ as I am standing down as Medical Director in December. I have been Medical Director since 2006 and before then was a Councillor of the then National Kidney Foundation of New Zealand from 1988 to 1997. During my time as Medical Director there have been many changes, not the least being the change of name to reflect a widened focus to include detection and management of early chronic kidney disease (CKD). KHNZ has been fortunate to have developed constructive links with staff at the Ministry of Health over recent years and now has an active role in the work of the National Renal Advisory Board (NRAB). I believe that KHNZ now has enhanced relationships with health professionals and patient support groups and increased recognition nationally.

The Board has completed work on a Strategic Plan for 2014 -17 and a Manifesto for consideration by the political parties in the next election. The Manifesto has seven points directed at increasing transplant rates, improving support for dialysis patients and education of general practitioners and practice nurses on the care of people with kidney disease.

In 2013/14 our priorities have been largely unchanged compared to recent years:

- Contributing to the National Renal Advisory Board's (NRAB) work on increasing live donor kidney transplants
- Developing resources for patient education
- Supporting the education of kidney health professionals
- Community education targeting groups at high risk of kidney disease
- Consulting with patient support groups
- Kidney Awareness Week and World Kidney Day activities

Chronic kidney disease (CKD) in New Zealand

The number of New Zealanders being treated for kidney failure continues to grow despite signs in recent years that this growth might have plateaued. Diabetes remains the major cause of kidney failure. The Australian and New Zealand Dialysis and Transplant Registry (www.anzdata.org.au) reports that at the end of 2012 there were 3,993 people being treated for kidney failure - 2,469 people on dialysis and 1,524 with a transplant – an increase of 3.4 per cent. 513 people started dialysis during the year compared to 477 the previous year. Fifty percent of dialysis patients manage their own treatment at home. There were 108 (50% live donor) transplants. Despite increases in live donation over recent years, the total number of transplants has not

increased for ten years and 600-700 people remain on the deceased donor waiting list. Most will wait several years for a transplant.

Transplantation

A lot of work is being done to increase live donor kidney transplant numbers and to address the longstanding shortage of deceased donor kidneys. The results of the investment of \$4 million by the Minister in 2012 "to encourage more organ donations" are now being seen. Organ Donation New Zealand now has more medical staff and transplant co-ordinators and is running programmes to expand the link nurse role in ICUs. There appears to have been an increased number of deceased organ donors so far this year.

The Live Kidney Donation Aotearoa programme, based in South Auckland and launched in March 2014, has produced three consumer resources – Becoming a live kidney donor, Live Kidney Donation and Being a Recipient – as part of their work to promote, inform and facilitate live donor kidney transplantation. The team has also developed a home-based Live Kidney Donor Education Programme using health educators from populations at high risk of CKD to build patient and whānau health literacy and is training lay volunteers who can provide information on kidney failure and live kidney donation. The number of people considering live kidney donation in South Auckland has shown a marked increase. The report on the feasibility of a national kidney exchange scheme was completed in February 2014 and identifies the options for a successful programme in the future.

A further \$4 million has been allocated in the last Budget for live donor kidney transplant services to fund a National Renal Transplant Service, with clinical leadership and more transplant co-ordinators with the aim of reducing inefficiencies in the current system and reducing barriers

to live kidney transplantation. Also funded is a part-time transplant co-ordinator for the Kidney Exchange programme.

Honorary Medical Advisors

In mid 2013, the Board appointed three Honorary Medical Advisors to work with the Medical Director and help the organisation with its work. The new advisors are Viliami Tutone, Counties Manakau DHB, Dr Jenny Walker, Northland DHB and Dr Colin Hutchison, Hawke's Bay DHB. KHNZ is grateful to these three nephrologists for volunteering their time and expertise for KHNZ.

KHNZ work with the Ministry of Health

KHNZ staff have been working with kidney and diabetes specialists, practice nurses and general practitioners on a National Consensus Statement on Managing Chronic Kidneys Disease in Primary Care. This document will guide GPs and practice nurses in the detection and care of people with CKD.

KHNZ's Chair, Medical Director and Chief Executive met with Cathy O'Malley, Deputy Director-General Sector Capability and Implementation in late 2013 to ensure that the Ministry included kidney health in the work of their Long Term Conditions.

Working with other organisations

KHNZ continues to work with Diabetes New Zealand and the Stroke Foundation sharing opportunities for raising community awareness, sharing consumer resources and contributing articles on CKD. An article by the Medical Director on CKD and diabetes was published in the Diabetes magazine in mid 2013 and KHNZ contributed to an Insight programme on Radio New Zealand on the challenge diabetes poses for our health system.

The Education Manager has been representing KHNZ on INFORMAS (International Network for Food and Obesity/NCD Research, Monitoring and Action Support). A national group is using the Government Healthy Food Environment Policy Index developed for assessing government policies and actions on food environments against good practice as part of INFORMAS which aims to monitor and benchmark progress on healthy food environments in different countries.

KHNZ carried out a short online survey of its communications with Patient Support Groups in May 2013. Ten of 16 groups responded. All respondents reported they used KHNZ's website and all found it helpful. The most helpful sections were general information for consumers, information on transplantation, news and access to information on Patient Support Groups.

Raising awareness of CKD in the community

The Medical Director contributed to two Radio New Zealand Insight programmes on diabetes and kidney transplantation. The Education Manager has been active talking to health professional and community groups about CKD. The very successful Warrant of Fitness campaign during Kidney Week is described elsewhere in this report.

In November 2013, a group of health professionals, staff of KHNZ, and supporters of all ages and cycling abilities competed in the Lake Taupo Cycle Challenge 2013 under the banner of "Kms for kidneys" to raise awareness of



CKD in our community. KHNZ are grateful to Rachael Walker, Renal Nurse, for helping organise the event and to Volkswagen New Zealand for providing cycle jerseys with messages about kidney disease and publicity.

Informing the health professional and community about CKD

The KHNZ website is the repository of all our educational material and the website has had a major overhaul to ensure it is accessible and easy to use. KHNZ website and the 0800 line are considered to be the prime sources of information for kidney consumers nationally. The popular KHNZ GP Guide (Chronic Kidney Disease (CKD) Management in General Practice) has been revised to keep it in line with national and international guidelines. "Know your numbers" is a new resource to help people with CKD understand what the results of their tests mean.

Research funding and support for professional development

The following kidney health professionals received educational support from KHNZ during the past year:

Lynne Olson, Renal Dietitian at Auckland DHB – \$2,000 – to attend the National Kidney Foundation Spring Clinical Meeting.

Lucy Robinson, Clinical Psychologist at Starship Hospital – \$2,000 to attend the 2014 European Working Party on Psycho-social aspects of Children with Chronic Renal Failure.

Jason Wei, Technical Advisor, Haemodialysis Services at Auckland DHB to attend the International Congress of International Society of Haemodialysis - \$2,000.

Julie Lawrence and Tessa Averill, Renal Nurses at Hawke's Bay DHB to attend the 2014 Home Therapies Conference- \$1,000 each.

Peggy Zhang and Rosella Tariq, Renal Nurses at Auckland DHB, to attend the ISPD Asian Chapter Conference - \$2,000 and \$500.

Helen Hoffman, dialysis educator at Wellington Hospital for a preceptorship at St Georges Hospital in Sydney- \$2,000.

The Board of KHNZ is currently revising its research funding strategy. As a result there will be new priorities for investment in research and education. Until this process has been completed KHNZ will not be seeking applications for research funding. It is anticipated that the new policy will be released in the near future.

National Renal Advisory Board (NRAB)

Kidney Health New Zealand acknowledges the work of Dr Marshall over the past three years of energetically

and skilfully overseeing the work of the NRAB as its Chair, particularly in the important area of transplantation. In late 2013, Dr Marshall resigned as Chair and Dr Murray Leikis from Wellington Hospital was elected to succeed him. Dr Leikis did his nephrology training in Wellington and Melbourne and returned to Wellington Hospital in 2006 as a full time Renal Physician. Dr Leikis has been the Clinical Leader of the Wellington Renal Service since July 2011. Two new members have been elected to replace Dr Marshall and Dr Van der Merwe – Dr Ian Dittmer from Auckland Hospital and Dr Chris Hood from Middlemore Hospital. KHNZ's involvement with the work of the NRAB is critical in enabling the organisation to achieve its goals.

Two prominent kidney health professionals recognised in New Year's Honours List

Professor Stephen Munn, transplant surgeon and Adrian Buttimore, dialysis clinician, are congratulated for being made Officers of the New Zealand Order of Merit at the New Year for their services to health. Both have made significant contributions to the care of people with kidney disease in New Zealand.

I am grateful to the Board of KHNZ, the other members of the Executive team, Carmel Gregan-Ford, Education Manager and Guy Johnson, Chief Executive, Deanne Hock, Administration, my nephrology colleagues and the many members of patient support groups for their support and advice over the past year.

Kelvin Lynn – *Medical Director*

Kidney Health New Zealand

2013-2014 Education Manager's report

This year seems to have been a time for updating and developing new resources. Our most popular resource "Living with Kidney Failure" Book has been updated and is now called "Living with Kidney Disease". We have used this opportunity to add a couple of extra chapters with increased information for patients and their families; we have made sure the content is relevant to New Zealand, as with all of our resources.

Together with our CEO, I visited Kidney patient support groups throughout the South Island to talk to them about Kidney Health New Zealand's Strategic plan and to identify key areas of need and where they see our role as the national organisation. These have been very useful as we plan our future work and we visited a number of support groups in the North Island later in the year and from this the Consumer Council was established.

We held our first Consumer Council meeting in February with kidney patients from around the country invited

to discuss issues that are important to them. KHNZ is committed to our mission for, Better Kidney Health for all New Zealanders and to be the lead organisation for improving kidney health and minimising the impact of kidney disease through, Research, Community awareness; education, support and advocacy. I now provide regular updates of our work to this group.

Resources

We have completed the "Know your numbers" resources which talks about blood tests and what the number means for each test. As our plastic kidney health check cards advise we recommend people get to "know your numbers". This has proved to be a popular resource with several requests for this already.

Another resource completed "If you have Kidney Disease we can help" brochure. This is designed to tell people about Kidney Health New Zealand and the services we

provide, so keep an eye out for these in your Doctors waiting rooms. These are distributed along with our GP Management Guide to Chronic Kidney Disease, which has just been updated.

The new Live Kidney Donor Network, which has been established as a result of Paula Martin's research into the barriers to live donation, has been very popular with more than 150 living kidney donors signing up to be included on our database and very keen to be involved, talking about their experiences and raising awareness about live donation. The inaugural meeting for this group has been set down for late July.

With funding approved last year, the long awaited and much requested educational DVD, which is aimed at people with end stage kidney disease and treatment options available, has commenced production; this is designed specifically to be a home grown New Zealand resource for kidney patients and their families. It will be translated into Tongan and Samoan languages initially.

Our website was upgraded to a more user friendly and easily accessible resource, this has seen an increase in requests for information via our Contact Us page. Interest in our Facebook page continues to grow. The 0800 information line continues to be well utilised with an average of 30 calls a month.

Kidney Health Week incorporating World Kidney Day

World Kidney Day aims to raise awareness of the importance of our kidneys to our overall health and to reduce the frequency and impact of kidney disease and its associated health problems worldwide. The theme for 2014 World Kidney day was Chronic Kidney Disease and Kidney Health New Zealand's aim was to target those most at risk.

Chronic kidney disease increases with older age, and for those with diabetes the risk is even greater. For those whose kidney disease is severe this leads to end stage kidney failure for which dialysis may be the only available treatment. The enormous health care costs associated with long term dialysis treatment are unsustainable, and there remains an unmet demand for kidney transplantation.

This year the Mad Butcher group agreed to distribute our Kidney Warrant of Fitness themed packs throughout all of their seventeen shops in Auckland. These packs were an envelope with a specially designed Warrant of Fitness label on the front. Included in the packs was urine testing kit, with instructions on use, information about Kidney Disease, and a plastic card with advice on what to ask your GP to do to check the health of your kidney.

We ran a radio advertising campaign telling people about the importance of early detection and prevention of kidney

disease, with Sir Peter Leitch voicing the commercials and encouraging people to visit their local Mad Butcher store to get a free Kidney Health WOF pack.

The response was overwhelming with the 3000 packs available gone before the end of the week. I was inundated with requests for more packs.

KHNZ also had a presence at Pasifika being held in Auckland where our Kidney Health Check packs were given out.

Work with other organisations

I have represented KHNZ on the International Network for Food and Obesity / non-communicable diseases Research, Monitoring and Action Support (INFORMAS) group. This group of 52 New Zealand-based independent public health experts, medical practitioners and NGO representatives rated the extent of implementation of policies on food environments and infrastructure support systems by the New Zealand government against international best practice.

We then identified and prioritised actions needed to address critical gaps in government policies and infrastructure support. New Zealand has an excellent opportunity to take the prevention of obesity and diet-related NCDs seriously, and invest in highly cost-effective policies and programs to become a leader in the field.

Following this I was invited to represent KHNZ on the Agencies for Nutrition Action organisation, the purpose of this group is "to reduce the premature death and disability caused by preventable lifestyle diseases such as heart disease, type 2 diabetes, stroke and certain cancers that are affected by poor nutrition and physical activity." This has been a great opportunity not only to contribute in an area that impacts on our patient group, but also the chance to network with other people and organisations passionate about improving the health of our communities.

In the past year there have been many requests to speak to service groups such as Rotary, Lions and WEA, as well as sessions for Post graduate nursing courses, workplaces and PHOs. I find these sessions particularly rewarding and another way to raise awareness about kidney disease.

Acknowledgements

I'd like to take this opportunity to thank Kelvin Lynn for his support and commitment to Kidney Health New Zealand. His passion and concern for those affected by kidney disease is obvious and during his time with KHNZ he has worked hard to ensure we are recognised as a reputable organisation. I wish him well in the next phase of his life and will miss his guidance.

Carmel Gregan-Ford RN, BHSc – *Education Manager*

Kidney Health NEW ZEALAND

Prevention • Support • Research

Treasurer's report 2014

The 2014 financial accounts, although not as successful as the previous year (because of a large bequest), nevertheless were on budget and produced a surplus.

Income was generated from the increased investment portfolio, bequests, fund raising and donations.

Expenses were on budget, which included funding the first of KHNZ's initiatives to set up a "Kidney Consumer Council"

and the production of a DVD to be used as an educational tool by Pre Dialysis Nurses for kidney patients.

A full set of audited accounts are available from the Secretary, Kidney Health NZ, Level 1/230 Antigua Street, Christchurch 8011.



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, Level 1, 230 Antigua Street, Christchurch 8011