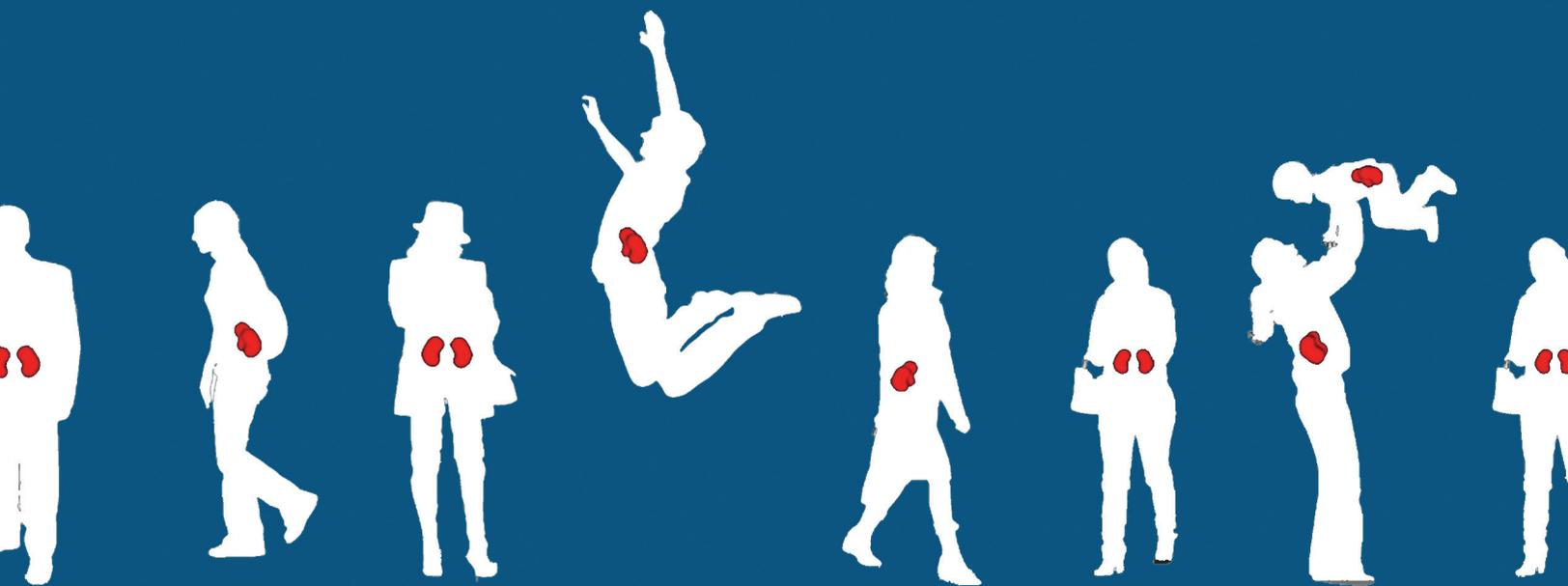


kiōney Health

NEW ZEALAND

Annual Report 2012/13



Kidney Health

NEW ZEALAND

Prevention • Support • Research

Annual Report for the year ended 31 March 2013

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)

Acknowledgements

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

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

Remembrance donations

Eve Chitty	Sherman Lowe
Karl Christensen	Jan Zygmunt Ratuszny
Ronald Michael Adams	Simon Daniels
Shiralee Leonie Walker	Jeffrey Baxter
Alistair McLachlan	Catharina Maria Read
Tania Marie Nacey	Ralph Cocklin
Sylvia Yalden	Freda Cooke
S. Gerald Duckor	Geoffrey Martin Sixtus
Ronald Mear	

Bequests

Estate Anne Clendon White
Estate Corry Rhys Walter Evans
Estate Antoine David Bahout

Donations - \$500 and over

Lotteries Grant	\$23,000.00
The Canterbury Community Trust	\$10,000.00
W.G. Johnston Charitable Trust	\$5,952.17
The Tasman Charitable Trust	\$1,000.00
Pharmacy Retailing (NZ) Ltd	\$6,000.00
Bryan R. Dyer	\$500.00



KHNZ contact details:

Website: www.kidneys.co.nz

Phone: 0800 KIDNEY (543639)

Charities number CC11348

Kidney Health New Zealand

2013 Chairman's report



Dave Henderson, Chairman

This has been an 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.

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.

Through our connections to government's National Renal Advisory Board (NRAB) we supported their development of a Five Point Plan which was presented to Health Minister Tony Ryal:

- 1** Piloting increased support at the three transplant services for three years;
- 2** Implementing current proposals for meeting 80% of live donor's lost incomes;
- 3** Support for the development of a national paired exchange scheme;
- 4** Funding live renal transplantation as a national service, to cover all costs associated with live donor transplantation;
- 5** Make increasing live renal transplantation one of the Government's health priorities for the next three years.

The Minister subsequently allocated \$4 million of funding based on this plan, with some modifications to what was taken on. KHNZ has during the past year monitored progress, and while there has been some, we are disappointed that progress in some important aspects has been limited. We continue to work with NRAB to try and get progress on the more thorny items.

Alongside the transplant focus is of course our work in support of patients and families, whether it is in support and consultations with regional Kidney Societies, or development

of education and information resources that are made public via our website. We thank the Ministry of Health for their ongoing assistance with the information project, 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.

We have also supported the important PhD research by Paula Martin, which we hope will help to shape a significant increase in the number of live donor transplants. Her work creates the opportunity for a new and more effective strategy to increase live donations in New Zealand, and I hope KHNZ will be able to build on that successfully in the coming year.

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, as well as the way KHNZ should respond to the changing environment for diagnosis and treatment of kidney disease. Government has a new awareness of the need to make sure renal services are up to date and as effective as possible, and we can help.

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

Kidney Health New Zealand

2013 Medical Director's report



Kelvin Lynn

Despite the uncertainties surrounding civic and residential repairs and rebuilds, KHNZ has continued to work with patient support groups, Diabetes New Zealand, the Ministry of Health and the National Renal Advisory Board. The work of the Executive is guided by the Board's Strategic Plan and the opportunities provided by our links with the Ministry of Health and the National Renal Advisory Board.

In 2012/13 our priorities have been

- Contributing to the National Renal Advisory Board's (NRAB) Five Point Plan for increasing kidney transplantation (see more below)
- Working with health professionals on the implementation of the plan and the projects arising from the \$4 million for kidney transplantation provided by Tony Ryall, Minister of Health
- 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

More international studies are confirming how common CKD is in communities like ours. It is likely that at least one in 10 adults has a sign of chronic kidney disease (CKD). Some studies suggest that there may be up to 750,000 New Zealanders with CKD. If one focuses on the more serious forms of CKD, there are likely to be 250,000 New Zealanders affected. These people with CKD are at increased risk of hospital admissions and heart attacks, and reduced life expectancy.

The Australian and New Zealand Dialysis and Transplant Registry (www.anzdata.org.au) reports that at the end of 2011 there were 2,381 people on dialysis and 477 started dialysis during the year. This represents a stabilisation of the total number of dialysis patients and a small fall in the number of new patients, possibly reflecting better management of diabetes and blood pressure in those at risk of CKD over recent years. When those patients with a transplant are included, there are 3,862 people on treatment for kidney failure. Diabetes remains the major cause of kidney failure.

New Zealand continues to be a world leader in home dialysis with 50 per cent of all dialysis patients receiving either home haemodialysis or peritoneal dialysis. There is a strong consensus amongst New Zealand nephrologists that home dialysis has advantages for many patients (and is also cheaper than centre and satellite dialysis) but there are concerns about the high rates of infection complicating peritoneal dialysis.

At the end of 2011, there were 1,481 people alive with a functioning kidney transplant but during the year only 118

transplants were performed. About 50 per cent of kidney transplants are from living donors (about a quarter take place before dialysis is needed) but, 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.

Five Point Plan and extra funding for transplantation

The following Five Point Plan developed by the National Renal Advisory Board was presented to the Minister of Health, Tony Ryall, in late 2011 asking him to:

1. Increase support at the three transplant services for staff to support patients and their families contemplating living kidney transplantation.
2. Put in place a scheme to meet 80% of live donor's lost incomes as a health programme.
3. Support the development of a national paired exchange scheme.
4. Fund live renal transplantation as a national service.
5. Make increasing live renal transplantation one of the Government's health priorities for the next three years.

The Minister responded positively by announcing an extra \$4 million in funding over the following four years "to encourage more organ donations". The money is to be invested as follows:

1. \$2 million to increase training and support for intensive care health professionals to identify dying patients who might become donors and give greater support to their families. This work will be done by Organ Donation New Zealand.
2. \$1.75 million to increase live organ donation, by employing dedicated staff who can support and guide family and friends while they make the decision to become donors. KHNZ submitted an application to carry out this work but was unsuccessful. The successful application was from Dr Mark Marshall from Middlemore Hospital. His work will focus on informing and supporting live donors and families in the Maori and Pacific communities of South Auckland.
3. \$250,000 to explore the option of establishing a national paired kidney exchange scheme. This work is led by Dr Ian Dittmer from Auckland Hospital.

Fair reimbursement of live donors' expenses remains to be addressed. The NRAB is working with the National Health Board to review the support for, and organisation of, kidney transplantation nationally.

Working with other organisations

KHNZ continues to share resources with Diabetes New Zealand. Research on results from the latest National Nutrition Survey published by researchers from the University of Otago in the New Zealand Medical Journal in March 2013 provides sobering reading and emphasises the need for all health agencies to work together to prevent and manage diabetes. This study found that seven per cent of the population has diabetes and one in five adults is at risk of getting it. Maori and Pacific, groups also at increased risk of CKD, have diabetes rates of 10 per cent and 15 per cent, respectively. The level of undiagnosed diabetes is worryingly high among younger (working age) adults. Only half of those adults under 45 knew they had diabetes.

KHNZ has worked with the Stroke Foundation on our common goals of reducing salt intake and improving the management of high blood pressure.

Informing the community about CKD

KHNZ continues to raise awareness about the need for those at increased risk of CKD to have a kidney check at their family practice through our website, now with its own Facebook page, online patient information resources, community meetings and the popular GP Guide (Chronic Kidney Disease (CKD) Management in General Practice). The revised version of Living with Kidney Disease has now been completed and copies sent to all kidney units. The booklet will be available on the NRAB and KHNZ websites. KHNZ appreciates the financial support from the Ministry of Health for printing the booklets. The KHNZ webpage is a popular source for information for consumers and health professionals. Recent additions to the website have been lay versions of the proposed Paired Kidney Exchange Scheme and the new tool for assessment of patients for the deceased donor waiting list.



KHNZ developed a card that people at risk of CKD can show to their GP to facilitate CKD testing. These have proved very popular.



Members of a family with a history of kidney disease getting a kidney check in Whangarei

Research funding and support for professional development

The following kidney health professionals received educational support from KHNZ.

Stella Friedlander, dietitian at Starship Hospital, Devin Mynett, pre-dialysis nurse at Auckland DHB, Frederic Doss, Haemodialysis Educator at Auckland City Hospital - \$2,000 each and Rachael Walker, Nurse Practitioner at Hawkes Bay DHB - \$1,000 - to attend the Annual Dialysis Conference in Seattle in March 2013.

Kathy Wintrup, nurse for the Southern DHB - \$750 to attend the Nephrology Educators Network meeting on the Gold Coast in February 2013.

Suzanne Joynt, Charge Nurse Manager at Auckland DHB - \$2,000 to attend the International Society of Haemodialysis Conference in Buenos Aires in September 2013.

Lyn Lloyd, Renal Dietitian at Auckland City Hospital - \$2,500 to support visit of Dr Alison Steiber to attend the ANZSN Annual Scientific Meeting and educate renal dietitians.

The PhD project, Increasing the rate of living donor kidney transplantation in New Zealand: Developing an evidence base, by Paula Martin at Victoria University was partially funded by KHNZ. Overall, Paula concluded from her research that "policy and practice in the wider system are not adequately oriented to supporting living donor kidney transplantation as the preferred treatment for end-stage renal failure". Paula has recommended a comprehensive national strategy for increasing New Zealand's living donor kidney transplantation rate that will be considered by KHNZ and the NRAB.

National Renal Advisory Board

KHNZ acknowledges the work of Dr Mark Marshall, Chair, and the members of the National Renal Advisory Board in addressing issues important to people with CKD and their families. It is imperative that the NRAB continues to receive support from the Ministry and DHBs for its work, in particular the new initiatives around transplantation and the continuation of the important annual audit of kidney units' standards of practice in dialysis and transplantation. The full board membership and minutes of the Board meetings are available on the NRAB and KHNZ websites.

KHNZ work with the Ministry of Health

KHNZ continues to work with the staff of the Sector Capability and Implementation Business Unit in the Ministry and acknowledges their support for our organisation. The Medical Director of KHNZ is an ex officio member of the National Renal Advisory Board and is thus closely involved with the work that the NRAB does with the Ministry such as the recently completed pilots trialling strategies for improved management of CKD in primary care. KHNZ is also involved in advising and supporting recent initiatives to increase rates of transplantation arising from the new funding in last year's budget. KHNZ believe that we can work more effectively with the Ministry in pursuit of our shared goals if the Ministry's work on CKD is integrated with that of the other long term conditions, as is the desired model in primary care.

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, 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 Education Manager's report

"I cannot believe that the purpose of life is to be happy. I think the purpose of life is to be useful, to be responsible, to be compassionate. It is, above all to matter, to count, to stand for something, to have made some difference that you lived at all."

- Leo Rosten



Acclaimed New Zealand actor, director and writer Michael Hurst O.N.Z.M has his annual kidney health check with his GP Dr Barney Montgomery.

Michael very kindly supported our focus 'if you have a family history of kidney disease you have an increased risk of kidney disease', as he has a history of kidney problems in his family. Our week focussed on encouraging family members to have a simple kidney check which included a blood pressure check and urine check for protein. Credit card sized cards were given out to family with information which they can take to their GP to have their kidney health checked.

In Northland and Christchurch letters were sent to patients on dialysis asking them to encourage their family members to get their kidneys checked. Kelvin and I, and the staff from the renal unit at Whangarei Base Hospital, spent World Kidney Day at Forum North in Whangarei testing family members and talking to them about the importance of maintaining a healthy lifestyle and getting checked annually. We were thrilled with the response we received with a large number of people coming along to have their kidney check and look forward to repeating it again soon. The local paper had two separate articles relating to the day in it throughout the week, also raising awareness.

Kidney Health Week coincided with the Stroke Foundations Salt Awareness Week, so together with the Stroke Foundation and St John's Ambulance we visited Weta Workshop in Wellington and provided free blood pressure checks and offered staff the opportunity to test their urine for signs of protein. Once again we were very pleased with the enthusiasm/interest the staff showed and were kept very busy. The synergy between salt and blood pressure was an ideal opportunity to work together, so it made good sense to pool our resources.

Renal Society of Australasia Conference (NZ Branch)

In November I was fortunate enough to attend the annual Renal Society of Australasia conference held in Whangarei, this conference provides an opportunity for nurses, doctors, renal dieticians, dialysis technicians and social workers to hear from a range of speakers on a variety of topics around kidney disease. I spoke about the role of Kidney Health New Zealand and the services we provided. This was a great opportunity as many of those attending were unfamiliar with our role, being either new to the renal area or not having the opportunity to hear about our organisation.

Kidney Information Forums

We held a Kidney Health Forum in Christchurch, which included Ashburton and South Canterbury Kidney Patient Support Groups. This was well received, but due to other commitments this was the only information forum held during the year.

0800 KIDNEY free phone line and Website

The last year has seen a continued increase in the number of calls I am receiving on the 0800 line, with in excess of 500 calls and emails. These are always acknowledged and information given as required. Our Facebook page is proving popular and a good way to raise awareness of current items related to kidney disease. We now have a number of overseas contacts.

Other activities

We attended a Health Day at Aranui High School in Christchurch, offering free kidney checks. It was great to see so many young people taking an interest in their health. I have had an increase in invitations to speak to service groups and post grad nursing programmes around kidney disease and its impact, which has been encouraging.

In April I was invited to be part of a steering committee, together with Rachael Walker from Hawke's Bay, which met monthly in Sydney to develop a tool that will assist people with end stage kidney disease to choose a treatment option that will be best for them. This project was very interesting, particularly as it highlighted awareness of the factors of perspectives from different parties involved in the decision making (patients, family, practitioners), that may enhance communication and improve the capacity for the patient and family involvement in shared decision-making. It is hoped that this will increase the number of people choosing to receive their dialysis treatment at home, as research shows many people do better when treated at home, but also ensure everybody has the opportunity to make an informed choice.

In August, Kelvin and I attended the Australia and New Zealand Society of Nephrology conference, held in Auckland, where we had a stand to promote our work and raise awareness of our resources; it was very well attended with the added incentive of a competition to win a cycling jersey.

It has been a busy year with it looking as though there are busier times ahead, as we continue to work to prevent kidney disease and support those with kidney disease.

Carmel Gregan-Ford, Education Manager

Living donor kidney transplantation in New Zealand: Barriers and solutions



Dr Paula Martin, Health Services Research Centre, Victoria University of Wellington

Like most countries, New Zealand is facing the problem of increasing numbers of people with end-stage renal failure. For many, a transplant from either a living or deceased donor is the best treatment and is more cost-effective than dialysis. But the gap between the number of people with end-stage renal

failure and the number of kidney transplants carried out each year is widening. New Zealand's very low rates of deceased organ donation mean that a transplant from a living donor often offers the best chance of getting a kidney transplant.

As a kidney donor myself in 2006, I have seen first-hand the benefits of transplantation to my recipient. Between 2010 and 2013 I carried out research into what might be done to increase NZ's current rates of living donor kidney transplantation. This is a complex problem and some of the findings are presented here.

Patient views about living donor kidney transplantation

Around 85% patients on the waiting list for a deceased donor kidney said they would accept a kidney from a living donor if someone offered and a third would prefer a living donor if possible. Despite these positive views, many patients had concerns about donors being out-of-pocket financially, donors feeling bad if the transplant failed, or the potential impact on donor health. Many commented that they were reluctant to approach family or friends about being a donor because of these concerns. A number had actually turned down offers from potential donors.

Information and education

Accurate information about all options for renal replacement therapy is critical for patients and their families and friends. Around 20% of patients on the waiting list said that no one from the renal unit had ever discussed living donor kidney transplantation with them. Many commented that discussions had been superficial, did not address their questions or were one-off. The focus on living donor transplantation often reduced over time. Family and friends also need accurate information. Without information, they may not even be aware that a living donor is needed or who could be a donor.

Finding a donor

The biggest barrier to organ transplantation is finding someone willing and suitable to be a donor. In living donor kidney transplantation, finding a donor is usually up to the patients themselves. Most health professionals are unwilling to be involved in the process of finding donors, although they will talk to potential donors who come forward. There is very little support for patients in how to raise the issue of living donation with their family and friends.

While many patients had discussed living donation with someone, nearly one fifth had not talked to anyone. Few had asked anyone directly to be a donor. Most patients would rather someone offered to donate without them having to raise the issue. However, people who did discuss living

donation were much more likely to have received at least one offer from a potential donor, than people who had not talked about it with anyone. Importantly, people who said they had discussed living donation with others were just as likely to have an offer as people who had asked someone directly.

Not everyone who offers to donate goes on to start the donor work-up process – some change their mind, some cannot afford to be out of work, some are dissuaded by other family members. Often patients themselves turn down offers, for example, because they have concerns about the financial or health effects on the potential donor, or because they assume (perhaps wrongly) that the person would not be suitable.

Donor work-ups

Nearly half of all potential donors who had started the work-up were incompatible with the intended recipient and nearly one-third were medically unsuitable. These are major barriers to living donor kidney transplantation. Options for addressing incompatibility now include ABO-incompatible transplants or Kidney Paired Exchange, where two or more incompatible donor-recipient pairs are matched so they can "swap" kidneys. Many patients had not heard of NZ's paired exchange scheme or had found it difficult to access. Some patients had turned down offers from people with the "wrong" blood type without knowing that paired exchange might be an option for them.

Patients had concerns about some aspects of the donor work-up, particularly the length of time taken (up to a year) and difficulty donors had in contacting transplant coordinators.

Conclusions

If New Zealand is to improve its current transplantation rates, a concerted effort and new approaches will be needed. There are a number of things that could be introduced including: better education and information for patients and their networks; supporting patients better to raise the issue of living donation with their families and friends; raising general awareness of kidney disease and living donor kidney transplantation; removing financial barriers for donors (especially reimbursement for lost income); better promoting NZ's Paired Exchange scheme and making it easier to access; and making the work-up process easier for donors.

Government funding in 2012 aimed at increasing living donor kidney transplants is a positive development but initiatives so far are piecemeal rather than part of a comprehensive national strategy. Such a strategy requires support from all major stakeholders including government, health professionals and patient groups such as KHNZ, and should be developed and implemented without delay.

This article is based on Paula Martin's PhD thesis "Increasing the rate of living donor kidney transplantation in New Zealand: Developing an evidence base" available from Victoria University of Wellington. Paula thanks Kidney Health New Zealand for a research grant which helped towards the cost of doing the research and thanks everyone who participated in the research, especially all the patients who filled in the survey and agreed to be interviewed.

Paula can be contacted at paula.martin@vuw.ac.nz.

Kidney Health NEW ZEALAND

Prevention • Support • Research

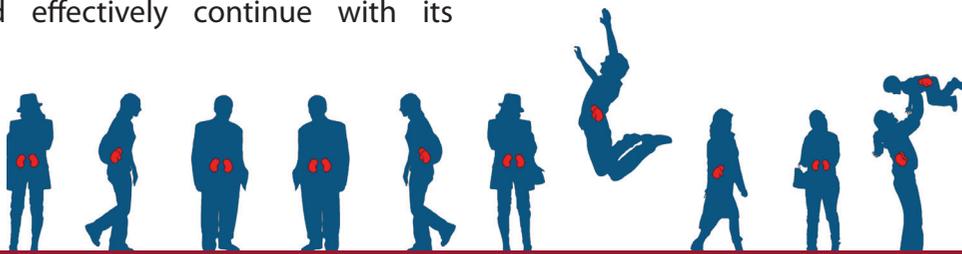
Treasurer's report 2013

2012/13 financial year KHNZ benefited from an increase in funding from bequests, donations and sponsorships.

Expenditure was kept to budgeted levels with exception of research which was increased. The resulting surplus will enable the Board to confidently and effectively continue with its

important strategic plans to carry out research, support and educate the increasing number of people affected by kidney disease.

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