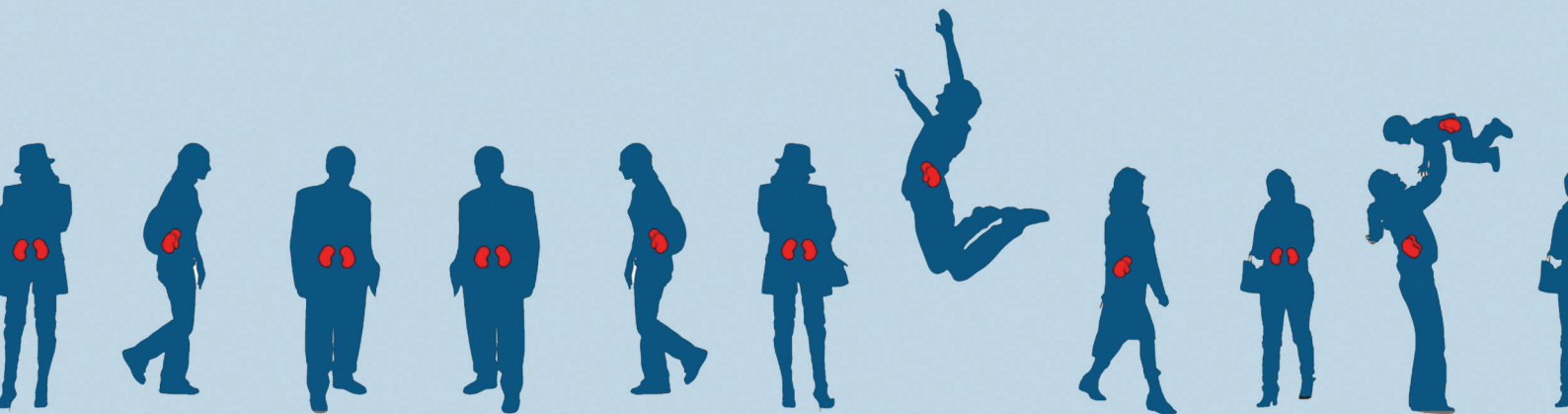


kidney Health

NEW ZEALAND

Prevention • Support • Research

Annual Report 2011/12



Board

The full Board is as follows:

Chairman	David Henderson (Wellington)
Treasurer	Assoc. Prof. Richard Robson (Christchurch) Dr David Voss (Auckland) (resigned November 2011) Mrs Nora Van der Schrieck (Auckland) Humphry Rolleston (Christchurch) Linda Grennell (Christchurch)
Secretary/Director	Guy Johnson (Christchurch)
Medical Director	Prof. Kelvin Lynn (Christchurch)

Acknowledgements

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

Roche Products (New Zealand) Limited
Craig Whitaker
Nick Polaschek – Senior Project Manager,
Sector Capability & Innovation Directorate,
Ministry of Health
New Zealand Renal Units

Remembrance donations

Brenda Papesch	Peter Darby
Arthur Forster	Delwyn Dyer
Judith Eleri Barclay	Leo Drury
Janice Elizabeth Brereton	Janice Gay Cudd-Smith
George Lum	Rex William Hudson
Jean Holloway	Stuart Appleby
Vicky Joy McIlroy	Mavis Taylor
Michael John Potter	Frank Daly
Jean Holloway	Rob Glen
Glen Soper	Ron Burgess

Bequests

Estate Clair Palmer-Jones
Estate Margaret Lesley Smith
Estates Ian and Joy McKinley

Donations - \$500 and over

Anonymous Donation	\$2,000.00
Pacific International	
Hotel Management School	\$1,074.23
Rapaki Maori Women's Welfare League	\$500.00

Kidney Health New Zealand

2012 Chairman's report



Dave Henderson, Chairman

The past year has seen continuing upheaval for our staff and Board members based in Christchurch, with families, homes, workplaces and schools still affected, and demolition visible in every direction from the office. I want to acknowledge the continuing achievements of everyone involved in keeping Kidney Health New Zealand not just ticking over, but achieving significant milestones in this trying and sometimes stressful environment.

The Board provides a framework for the efforts of our staff through our Strategic and Business Plans, structured around the implementation of our Vision: Better Kidney Health for All New Zealanders. For their significant volunteer contributions to the planning process, and their input into the running of the organisation, I warmly thank the Board members: Treasurer Richard Robson, Nora Van der Schrieck, David Voss, Linda Grennell and Humphry Rolleston. The reports from our Medical Director, Kelvin Lynn, our Education Manager, Carmel Gregan-Ford, and our Director, Guy Johnson, provide details of the achievements of KHNZ. Sincere thanks to them and to our Administrator, Deanne Hock.

A key event this year was the very successful function at Government House in Wellington, marking World Kidney Day. His Excellency the Governor General, who had generously agreed to continue the role of his predecessors as our Patron, helped us celebrate the Day and in particular the very special gift of one human being to another, that is kidney donation.

I noted on the day that an increasing number of NZers are in need of a kidney, and that this needs to be matched by an increasing number of NZers who are choosing to donate one. The donation of a kidney helps not just the individual recipient but all their family and whanau, as kidney disease can progressively undermine one's ability to work and earn an income, to play sport, to pursue hobbies, to take the kids on holiday or to go as parent support on a school camp. Ultimately, it can shorten one's life. The donation of a kidney can change all that and this huge gift should certainly be celebrated.

I commented to His Excellency the Governor General, what the gift of a kidney has meant for me. After I received a kidney over 3 years ago, my life has completely changed; from working part-time to now more than full-time, and being able to be fully involved in family, fitter and healthier and full of appreciation for life.

Increasing the frequency of kidney donation is a significant goal in our Strategic Plan, and is actively supported by the National Renal Advisory Board, which advises the Minister, the Ministry and the District Health Boards. We are ably represented on this Board by our Medical Director, Kelvin

Lynn, and our consumer representative, Michael Papesch.

We also work directly with the Ministry of Health, developing information resources for renal patients, their family and whanau. This includes answering such questions as who can donate, what tests are involved, the opportunities for donation to a relative or family member, and the financial support that is available. Details on this work are available to all online at www.kidneys.co.nz and www.moh.govt.nz/rab.

We will continue to work with the Ministry on other issues identified in our Strategic Plan and in our workshops with patient support groups around the country. Many of our priorities are reflected in specific funding proposals put forward to the Ministry for consideration in Government's 2012 Budget. I want to specifically thank Minister Ryall for his consideration of these proposals, and also Michael Woodhouse MP, whose Private Member's Bill in Parliament has been so helpful on these issues.

Research shows very clearly that there are significant financial savings to be made with kidney transplantation. Keeping people on dialysis is expensive and the cost is growing as the number of people needing it grows. While there is an upfront cost for the transplant operation, the longer term costs for a successful transplant are much less. Just as importantly, transplantation can significantly extend the recipient's life.

Another key priority is the continuing link we have with local patient support groups, providing information and a series of regional workshops and information days. Patient support groups are also regular users of our information resources, either through the website or the 0800 KIDNEY (0800 543 639) information line.

Thanks to the work of our Executive Director and Treasurer we completed the past financial year with a controlled level of expenditure. We have taken steps to reduce expected costs and manage our assets responsibly.

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

Kidney Health New Zealand

2012 Medical Director's report



Kelvin Lynn

Ongoing aftershocks, the new realities of working with EQC and insurance companies, geotechnical assessments and the rapidly changing face of the Christchurch CBD have continued to affect the staff of KHNZ. We are now fortunate to be housed in a modern building, more suited for our purpose, albeit surrounded by wasteland and opposite a soon to be demolished brewery. Despite the unsettled times we have been able to continue our work with patient support groups, Diabetes New Zealand, the Ministry of Health, Parliamentarians and the National Renal Advisory Board.

Our main goals for 2011/12 have been:

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

Chronic kidney disease (CKD) in New Zealand

It is likely that at least one in 10 adults has a sign of chronic kidney disease (CKD) if the figures from studies in other countries can be applied to New Zealand. If all forms of CKD, even the most minor, are included there may be up to 740,000 New Zealanders with CKD. If one focuses on the more serious forms of CKD, there are likely to be 250,000 people affected. These more serious forms of CKD can lead to kidney failure and increase the risk of cardiovascular disease (heart, stroke and blood vessel disease) the leading cause of death in New Zealand, accounting for 40% of deaths annually. The New Zealand Health Survey managed by the Ministry of Health will begin to collect blood and urine samples as well as other health information and this will lead to a better assessment of the burden of CKD in New Zealand.

KHNZ are able to raise awareness about the need to detect and manage CKD early through our website, now with its own Facebook page, online patient information resources and the popular GP Guide (Chronic Kidney Disease (CKD) Management in General Practice). A joint programme supported by the National Renal Advisory Board and the Ministry of Health is looking at four pilots of management of CKD in primary care. It is hoped that the results of these pilots will guide future planning of the delivery of CKD care in the community.

The Australian and New Zealand Dialysis and Transplant Registry (www.anzdata.org.au) and the seventh annual New Zealand Dialysis and Audit report (www.moh.govt.nz/nrab) report that at the end of 2010 there were 2,378 people on dialysis and 503 started dialysis during the year (a rate more in keeping with the numbers before the 2009 "spike"). Diabetes remains the major cause of kidney failure. The incident rates for dialysis vary markedly across the country from 47 new patients per million population (pmp) in Christchurch to 212 pmp in South Auckland. Renal units serving populations

with a high proportion of Maori and Pacific people have the highest rates of people on dialysis. New Zealand continues to be a world leader in home dialysis – 35% of all dialysis patients are on peritoneal dialysis and 18% on home haemodialysis. At the end of 2010, there were 1,403 people alive with a functioning kidney transplant but during the year only 108 transplants were performed, the lowest number since 2006. Of these, 44% were deceased donor transplants and 56% from live donors.

Regional services for CKD

There have been welcome initiatives to address the needs of people with CKD who live outside the main metropolitan centres. In the Central region, a groups of doctors, nurses, managers and representatives from the Wellington Region Kidney Society have been working to develop a Renal Integrated Care Strategy. Similar work in Waikato has produced the Midland Regional Renal Plan. The greater Auckland region now has a comprehensive renal service for the people of the Waitemata DHB. There is a stable nephrology workforce in New Plymouth, Palmerston North and Hawke's Bay. Expansion of the Kidney Society's (formerly the Auckland District Kidney Society) services to cover the Midland region as well as Auckland and Northland provides important support for people needing treatment for kidney failure. Satellite dialysis units have been established in Tauranga, Rotorua, Kawakawa, Kaitaia, Porirua and Gisborne and dialysis houses are now available in South Auckland and Wairoa.

Working with Diabetes New Zealand

A poster reporting the collaboration between KHNZ and Diabetes NZ won the Best Poster Prize and the International Federation of Kidney Foundations meeting in Vancouver in April 2012.

Liaison with other support groups

Patient support groups continue to provide an essential local resource for people with CKD. The Medical Director and Education Manager attended the following meetings of patient support groups in 2011 – Whanganui 8 September, Taranaki 10 September and Wellington 29 September.

World Kidney Day 8 March 2012

The theme for the seventh WKD was Donate - Kidneys for Life – Receive and our activities were co-ordinated with Organ Donation New Zealand. Highlights were two receptions

to recognise live kidney donors hosted by the Governor-General in Wellington and Mayor Len Brown in Auckland and the planting of freesias to commemorate organ donors co-ordinated by ODNZ and local patient support groups. The annual visit to the Beehive to perform kidney checks on the MPs and staff went ahead as usual with the help of the kidney team from Wellington Hospital. Print and social media coverage was excellent. Despite initial interest, none of the TV channels provided coverage. The week's activities were effective in publicising the benefits of organ donation and in recognising live kidney (and liver) donors. Further information is available in the Education Manager's report.



Live kidney donors with The Governor-General, Lt Gen Rt Hon Sir Jerry Mateparae, at Government House, Wellington

Research funding and support for professional development

The Board resolved to provide research funding of \$14,990 to Paula Martin at Victoria University for her study entitled "Strategies for increasing rates of live transplantation in New Zealand". The other research project currently supported by KHNZ is "A critical bioethics of kidney health: An ethnographic and philosophical investigation", Dr Rhonda Shaw (\$57,782) Travel Grants, each of \$1,000, were awarded to: Julie Pesirla (Waitemata DHB), Natasha Darby (Hawke's Bay DHB), Julia Bates (Counties Manukau DHB), Jude Kearns (Capital and Coast DHB) and Blair Donkin (Southern DHB) to attend the Home Therapies Conference in Sydney March 2012. Carol Woolf, Social Worker (Canterbury DHB) received \$500 to attend a psychotherapy training course.

KHNZ work with the Ministry of Health

KHNZ continues to work with the staff of the Sector Capability & Innovation Directorate in the Ministry. The work that KHNZ is doing fits in well with the new ways the Ministry will target assessment and management of significant long term conditions, such as diabetes and heart disease. Our aim is for detection and management of CKD to be included within these programmes. KHNZ acknowledges the support of Margie Apa, previous Deputy Director General of this Directorate, and looks forward to working with her successor and other staff of the Directorate.

KHNZ has completed a number of projects, funded by the Ministry of Health, over the past year. Carmel Gregan-Ford, Education Manager, led a wide ranging group of stakeholders in developing three new resources related to supporting people with kidney disease - Income support, Transport and accommodation support and Dealing with loss and grief. The Medical Director, together with Dr Tonya Kara of Starship Hospital, developed five resources on kidney disease relevant to children and their families. These resources are available at www.kidneys.co.nz and www.moh.govt.nz/nrab.

KHNZ has obtained financial support from the Ministry for a revision and reprint of the booklet given to all patients with advanced kidney disease - "Living with Kidney Failure". The revised version will be available later in 2012. KHNZ continues to pursue the following issues of mutual interest with the staff of the Ministry of Health:

- increasing financial compensation for living kidney donors
- streamlining access to assessment and surgery for kidney donors and recipients
- recognition and financial support for people on home dialysis
- improved regional co-ordination and access to renal services
- funding of patient information resources and support for best practice guideline development and implementation
- continued support for the work of the NRAB

National Renal Advisory Board

Dr Mark Marshall, Chair, and the members of the National Renal Advisory Board are pursuing a very productive work stream, particularly around increasing support for live kidney donation. The full board membership and minutes of the Board meetings are available on the NRAB and KHNZ websites. Issues being addressed over the past year by the NRAB that are of interest to KHNZ are:

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

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

Dr Peter J Little MB ChB, FRACP, FRCP

15/11/1930 to 19/5/2011

Peter Little, the founder of the Christchurch renal unit and a pioneer of home dialysis in New Zealand, died during the past year. In 1966, Dr Little was appointed as Canterbury's first nephrologist to set up a renal unit at Christchurch Hospital. The unit provided home dialysis training for patients throughout New Zealand. He was Head of the Nephrology Department from 1976 to 1979. During this time he recruited Adrian Buttimore to manage the dialysis service and encouraged a number of young doctors to become nephrologists including Ross Bailey, Al Gillies, Kelvin Lynn and Jim Neale. The principles of treatment for people with kidney disease that he established still influence the treatment of people with kidney failure today. In 1980, Dr Little established a renal unit in Saudi Arabia and subsequently worked in Baghdad, before retiring in New Zealand.

Kidney Health New Zealand

2012 Education Manager's report

I'd like to say it has been a more settled year, but the aftershocks we continue to experience would certainly make that a bold statement. In spite of this we have managed to continue our work and look to the future with confidence, as we increase the profile of kidney disease and provide information, education and resources to the general public and those with kidney conditions.

Kidney Health Week (incorporating World Kidney Day)

On March 8 2012 transplant recipients around New Zealand said 'thank you'. Thank you to their donor, donor family, health professionals, support people, employer—anyone who has helped them on their transplantation journey. The first Thank You Day in New Zealand was organised by Organ Donation New Zealand (ODNZ), in conjunction with Kidney Health New Zealand, and took place on World Kidney Day 2012. The Thank You Day was part of Kidney Awareness Week and this year the theme was transplantation and organ donation (of all organs—not just kidneys).

Recipients planted freesia bulbs, generously donated by Oderings, in public places throughout the country on 8 March. The freesias symbolise the new beginning they have been given thanks to the generosity of others. The aim of the Thank You Day was to raise awareness about organ donation and transplantation and encourage people to have a conversation with their families about their wishes should they ever be in a situation where organ donation is possible.

We were pleased with the media coverage, but we would have loved something on television. We obviously aren't sensational enough! However, I have received a large number of calls, and inquiries via our website, regarding kidney donation following the campaign, so the message is getting out there. It was great to work with Organ Donation New Zealand and the feedback has been very positive.

The Mayoral reception in Auckland with Mayor Len Brown was a lovely occasion with a number of living donors recognised for their selflessness and generosity and given a certificate in recognition of this. Lee Martell was also recognised for being the longest surviving kidney transplant recipient in New Zealand, having had her kidney for 40 years. The Governor General hosted a similar function at Government House, which was a wonderful celebration, and very well received by those who attended.



The Governor General with Becky Pham and kidney donor David Pham and Dr Murray Leikis.

Our annual visit to the Beehive on March 6th, saw us continuing our tradition of kidney health checks for MPs and the staff working in Parliament, with many of them returning year after year. Once again our thanks go to the wonderful staff from the Wellington Renal services that are always willing to help out, and MP Jo Goodhew for hosting us.

Home Therapies Conference

I attended the Home Therapies Conference, "Breaking down the Barriers" in Sydney; this was a very interesting conference with a variety of international and local speakers. The theme of the conference "Breaking down the barriers" was evident in many of the presentations and discussions I attended. The most important take home messages for me were: enabling equity of access, ensuring informed choice to maximise lifestyle and "Home First" should be a national approach. Needless to say we have a lot of work to do before these can all be achieved, but I think New Zealand is one of the leaders in promoting home therapies as a preferred treatment option.

Kidney Information Forums

Every year we run Kidney information forums, around the country. These have replaced our annual kidney support group conference, so that more people are able attend without having to travel long distances. We invite local speakers and utilise the staff from the local renal service where possible. Forums were held in Wanganui, New Plymouth and Wellington/Porirua in 2011 and more are planned for 2012.

0800 number and website

The 24 hour free phone information line has received an average of ten calls per week, many of these from people thinking about being a living kidney donor, newly diagnosed with kidney disease, looking at treatment options and some just wanting to talk about their illness. We receive many requests for information via our increasingly busy website. We launched our Facebook page in October last year to raise awareness of kidney related issues and this is slowly gaining momentum. Every little bit helps.

Other activities

In July I was asked to provide some education and screening for the staff at Griffiths in Auckland. This was a good opportunity to work with the Occupational Health Nurse and staff. The feedback I received following the visit was very positive, with several people visiting their GP following their check.

I continue to provide lectures to nurses attending post graduate courses as required as well as a variety of service groups.

We have added several more information sheets to our web based resources, which can also be found on the Ministry of health website. Kelvin has mentioned these in his report. Once again the feedback regarding these resources has been positive. We look forward to completing several more resources in the coming months.

Carmel Gregan-Ford, Education Manager

Annual Report

Guy Johnson, Executive Director

It is five years since the New Zealand Kidney Foundation changed its name and many of its objectives to a more proactive Kidney Health New Zealand and we can be proud of our achievements. A generous bequest gave us a good financial base which we continue to build on. Funding has enabled us to employ a Medical Director and an Education Manager and this in turn has ensured that the voices of those with kidney disease and their families and carers can be heard across the community and Government jurisdictions.

In the last two years we have been working closely with the Ministry of Health and National Renal Advisory Board. For the first time we can sit around the table and be recognised as an important facilitator for the dissemination of information to those with Kidney Disease and their families. Whilst we have made big gains in some areas, we are still frustrated that we have not been able to achieve more in the important area of transplantation. Unfortunately the increased numbers of living donors have been offset by a fall in the number of deceased donors. Hopefully in the next few years we can turn this situation around.

Any organisation is only as good as its people and I would like to thank our supportive patron, the Governor General Lt Gen The Rt Honourable Sir Jerry Mateparae, The Board ably led by the Chairman David Henderson, Medical Director Professor Kelvin Lynn, Education Manager Carmel Gregan-Ford, sponsors, who are helping to make a difference to the lives of those with Kidney Disease in New Zealand.



KHNZ Research Grant

Paula Martin

In 2006 I donated a kidney to my husband. At the time, I was just focusing on getting through the year long donor work up and supporting my husband while we coped with the impacts on our lives of him being on peritoneal dialysis. Only after the transplant did I realise just how few living donor transplants are done each year in New Zealand. In 2006, only 46 other live donors gave a kidney to someone; last year the number had climbed to 57 live donors, but the number of people needing a transplant had also increased dramatically, with around 600 on the official waiting list.

What could be done to increase the current rate of kidney donations? The low number of transplants is a concern because we know that for most people with end stage renal failure, a transplant is the best treatment. In addition, it is cheaper than keeping people on dialysis. In order to develop solutions, we needed research to tell us what the barriers to living donor kidney transplantation are in New Zealand; how similar to, or different from, barriers in other countries these are; and what people involved in the renal community here think could be done about those barriers, so that more people wanting a transplant can get one.

In 2010, I decided to do some research on this topic to fill this gap. Supported by a research grant from Kidney Health New Zealand, I'm currently undertaking a PhD in Public Policy based at the Health Services Research Centre in the School of Government, at Victoria University of Wellington. My focus is solely on living donation, not deceased. Around half of all kidney transplants now come from living donors and with the increasing demand for kidney transplants and the shortage of deceased donors, living transplantation has to be a critical part of solving the problem. The barriers to living donation and deceased donation are different so it's important to think about them separately.

We know from overseas research that there can be many different barriers: for example, patients needing a transplant often find it difficult to approach their family and friends about whether they might consider living donation; people who want to be donors can face practical barriers such as loss of income while they take time off to recover from the surgery; and many people who would like to be donors discover that they aren't compatible with the person they want to donate to, or that they have a medical problem of their own which makes them unsuitable. A particular problem in NZ is that Maori and Pacific people often find it harder to get a transplant than European/Pakeha. There are likely to be many different reasons for this. Cultural attitudes to organ donation may be one factor, but a bigger issue may be that it can be harder for these patients to find a donor who meets the strict medical suitability criteria because of things like the high rates of Type II diabetes in these populations.

There is no single solution to this problem – this is an extremely complex issue and we'll need a variety of different initiatives to make a difference to it. So, I've been looking at our legislation and current policies as well as how renal services operate on the ground, and talking to a range of different people – patients, renal specialists, transplant coordinators, patient support groups, managers in District Health Boards and senior government officials and politicians – to find out what they think the issues are.

Finding out what the issues are from a patient perspective has been a big part of the research. With the assistance of the three renal transplant units, I carried out a postal survey last year of all the people on the kidney transplant waiting list and received nearly 200 replies. I've followed that up with a small number of in-depth patient interviews. The early results of this part of the research suggest that, as in other countries, patients find it very difficult to "ask" someone to be a kidney donor which often stops them talking to their family and friends about living donation. Furthermore, patients that do get offers from people to be kidney donors often find they are incompatible or the potential donor is medically unsuitable for some reason. Health professionals I've interviewed have provided valuable insights into what the issues are from their perspective inside the health system.

I'm aiming to finish this research in 2013. I hope it will be of use to practitioners, policy makers, patient groups and anyone else interested in making a difference to this problem.

Contact details: paula.martin@vuw.ac.nz

Thanks to Kidney Health New Zealand for supporting this work with a grant towards the costs of doing research.

Kidney Health NEW ZEALAND

Prevention • Support • Research

Treasurer's report 2012

2011/12 was another difficult year financially for KHNZ. Increases in income from fundraising, bequests and donations were offset by the loss of revenue generated by the annual sponsored nurses conference which was cancelled this year.

Once again the Board had to make the decision as to whether to reduce expenditure to meet the

income or use capital to continue to fund our objectives. They chose the latter which incurred a 40k deficit for the year.

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