

ANNUAL REPORT

FOR THE
YEAR ENDED
31 MARCH
2018



Chairman's Report



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(Wellington)

Chairman from Jan 2018

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(Auckland)

Humphry Rolleston
(Christchurch)

Nick Polaschek
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Max Reid
(Dunedin)

Medical Director

Dr Colin Hutchison
(Hawkes Bay)

National Education Manager

Carmel Gregan-Ford
(Christchurch)

Administrator

Deanne Hock
(Christchurch)

Fundraiser (commenced March 2018)

Jacqui Jeffrey
(Christchurch)

CONTACT DETAILS

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Website: www.kidneys.co.nz

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Kidney Health New Zealand

The vision of Kidney Health New Zealand is better kidney health for all New Zealanders. The way that we seek to achieve this is through four organisational goals:

1. KHNZ is the leading advocate for world class kidney health care in NZ
2. KHNZ is a primary source of reliable and relevant information on the prevention and management of kidney disease
3. KHNZ is the national voice for people with kidney disease and their families
4. KHNZ will commission research to support the KHNZ's objectives.

Over the 2017/18 year, very good progress was achieved across a number of fronts to improve kidney health care in New Zealand, due in no small part to the work of KHNZ. Three issues stand out in 2017/18.

First, progress was made on the passage of the Financial Assistance for Live Organ Donation Bill and the subsequent unanimous adoption by Parliament of the re-titled Compensation for Live Organ Donors Act. The new legislation lifts the financial assistance available to live organ donors from the equivalent of the sickness benefit to full compensation for lost earnings. KHNZ made a significant contribution to this process, lobbying MPs across the political spectrum for their support of increased financial assistance for organ donors and presenting a strong written and oral submission to the Health Select Committee supporting full compensation for lost income and management of the new regime being shifted from WINZ to the Ministry of Health.

Second, we made an equally significant contribution to the development of the Deceased Organ Donation Strategy, launched by the Government in June 2017. Our Chief Executive represented KHNZ on the initial expert advisory group that reviewed existing deceased organ donation practice in NZ and overseas, and on the subsequent sector working group that drafted the final strategy. Fully implemented, this strategy will make a significant difference to the rate of deceased organ donation in New Zealand, an area where we lag behind the rest of the world. We have pressed the incoming Minister of Health to implement the Strategy in its entirety, and expeditiously.

Third, KHNZ has been at the forefront of promoting and supporting the Ministry of Health's "Primary Care CKD initiative" which intends to facilitate earlier identification and treatment of patients with early stage chronic kidney disease. KHNZ's role in 2017/18 had been to develop and coordinate the delivery of a series of education modules for GPs and other health professionals working in the primary healthcare setting, and (with an estimated 10% of the NZ population living with undiagnosed kidney disease) to promote awareness of the disease and the importance of early diagnosis.

As well as supporting these strategic opportunities to improve kidney health care in New Zealand, over 2017/18 the Board of KHNZ has focussed on three opportunities to strengthen the governance of KHNZ.

First, the Board has developed a new, modern constitution for KHNZ which is expected to be formally adopted at the November 2018 AGM. As well as updating the constitution to reflect the modern realities of KHNZ, the new constitution puts in place proper arrangements for the appointment and term of Board members, including a separation of the Board and management, and a limit on how long Board members can serve. As a result of these changes, long-standing Board members will be retiring over the next 2-3 years, so that new faces and perspectives can come onto the Board as part of the overall renewal of KHNZ.

Second, in early 2017 the Board agreed to terminate its telemarketing fundraising contract amongst concerns about how the fundraising was being handled. Since then, the Board has been developing a new funding raising strategy for KHNZ, intended to diversify the fundraising base of the organisation. This will take some time to fully develop and implement. As a result, the Board expects KHNZ to make a small cash loss in the current (2018/19) financial year, but we consider the financial position of KHNZ can sustain a short term deficit.

Third, the Board has been developing a new strategic plan for KHNZ to succeed the previous strategic plan that ended in 2017. The 2014-2017 Strategic Plan emphasised KHNZ's advocacy role, and we have seen some significant achievements (such as the new organ donation initiatives outlined above). For the next three years, and subject to funding being secured, we see an opportunity for KHNZ to move progressively to providing national services to renal patients and their families. These would sit alongside, and not overlap or duplicate, the critical services provided to regional kidney support groups and societies. Delivering on this potential will be a key area of focus for the Board over 2018/19 and beyond.

The planned adoption of the new constitution will lead to changes in the KHNZ Board in 2018/19, as Board members retire to give effect to the limit on how long Board members can serve in total. At the next AGM, long standing Board members Nora van der Shrieck, Dave Henderson and Humphry Rolleston will stand down. They have been excellent servants of renal patients and their families over the many years that they have served. On behalf of renal patients up and down New Zealand, I would like to acknowledge and thank them for their service.

Michael Papesch
Chair, Kidney Health NZ



Chief Executive's Report

Kia ora tatou katoa

The year ended March 2018 has proved to be another year of both opportunity and challenge for Kidney Health New Zealand. Certainly it has been a year of significant activity.

In the run-up to the 2017 General Election, KHNZ developed a pre-election 'Manifesto', which was distributed to the then Health Minister and the health spokesperson for each of the other political parties. The Manifesto acknowledged the significant progress that had been made for renal patients since the 2014 election, including:

1. The review of deceased organ donation practice in New Zealand and the subsequent development of a national strategy for increasing New Zealand's rate of deceased organ donation.
2. The increase in both the overall number of kidney transplants and those pre-emptively offered (i.e. patients receiving a kidney transplant before needing to go onto dialysis).
3. The passing of the Compensation for Live Organ Donors Act in late 2016 providing 100% reimbursement of lost income for live organ donors, and
4. The rollout across New Zealand of the Ministry of Health's initiative to prioritise early identification and intervention for CKD patients in the primary healthcare setting.

Nevertheless, the Manifesto also acknowledged that there was much still to be done. The 2017 Manifesto set out a further two priorities that KHNZ continues to believe are fundamental to continuing the progress already made in improving the health and wellbeing of the growing number of renal patients in New Zealand, and ensuring that New Zealand offers world class renal services:

1. Ensuring that the implementation of the Government's Strategy for Increasing Deceased Organ Donation is sector-driven and adequately funded
2. Ensuring timely, equitable and nationally consistent delivery of dialysis treatment

In a subsequent briefing to the incoming Minister of Health, the Hon Dr David Clark, KHNZ reiterated these concerns. Likewise, KHNZ has continued to lobby both the Minister and Ministry of Health for the development of a suite of minimum standards for renal care in New Zealand. While it is well-recognised that Maori and Pacific patients contribute disproportionately to New Zealand's renal population, that they are unable to access the same levels of renal care as the rest of the population remains a statistic that KHNZ believes should be challenged. So too with rural renal patients – who again, struggle to receive the same level of support and access to care as their urban counterparts.

Over the course of the 2017/18 year the KHNZ team has delivered or facilitated over a dozen education sessions or conference presentations. Our National Education Manager has responded to close to 700 calls to our 0800 helpline and responded to hundreds of email enquiries. The organisation has maintained its strong public presence, with a number of meetings with key politicians and Ministry of Health officials held, and media releases and comment made when the opportunities for these has arisen.

KHNZ has also lead a joint KHNZ-District Health Board review of what has come to be termed 'away from home' dialysis. Research undertaken by KHNZ during the year showed that virtually every dialysis unit in New Zealand was struggling to meet the demands of its own dialysis population, let alone anyone seeking dialysis from 'out of district'. A comprehensive review of dialysis service provision resulted from this work, and a number of recommendations as to how renal units' capacity to accommodate patients requiring dialysis from elsewhere in the country (and from overseas) developed. In the year ahead, we intend to work with renal units across the country to explore the possibility of KHNZ providing national coordination of 'away from home dialysis'.

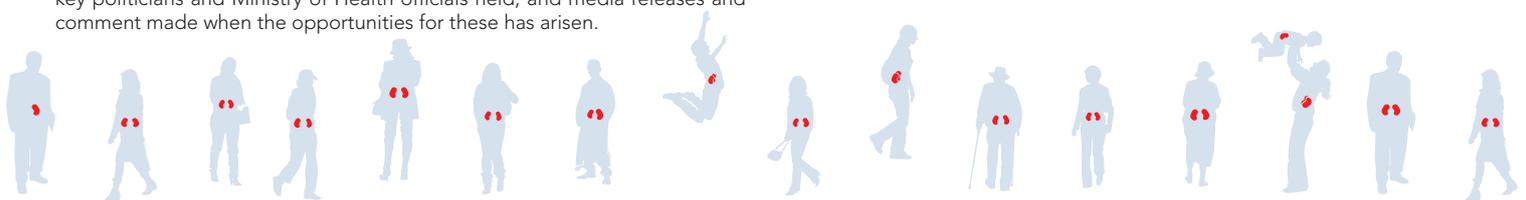
The organisation is also planning to pilot a national CKD screening programme, furthering our commitment to the early identification and treatment of individuals with early stage chronic kidney disease. We are also exploring potential research and development partnerships to improve both physical and mobile application-based accessibility to renal services and support.

Inevitably, the greatest challenge and constraint facing an organisation such as Kidney Health New Zealand continues to be funding. And while, as is noted elsewhere in this Annual Report, KHNZ has adopted a comprehensive fundraising strategy and, for the first time in the organisation's history, appointed a part-time Funding Coordinator to manage the strategy's implementation, the year ahead will be a challenging one from a financial perspective. However, we continue to trust in the generosity of the individual donors and trust and grant sources that have supported the organisation in the past, of those who are increasingly recognising the value of our work and contributing to as they are able.

In similar vein, the ongoing support of the Kidney Health New Zealand staff team and Board must also be acknowledged. Now into my fourth year in the CEO role, I still encounter a surprised reaction when those – familiar with our work, but not necessarily with our organisational structure – discover that our not insignificant contribution to the sector is made by, essentially, four 'part-timers'. Together with Carmel Gregan-Ford (National Education Manager), Deanne Hock (Administrator) and Dr Colin Hutchison (Medical Advisor) and, more recently, Jacqui Jeffrey (Fundraising Coordinator) KHNZ continues to make a contribution that clearly belies our small size as an organisation. That contribution could only have been made through the commitment and dedication of our team. My thanks, also, to KHNZ's equally committed Board membership – particularly this past year, as the Board has begun the task of reviewing and re-visioning KHNZ's strategic direction. Together, we continue to pursue the organisation's vision of better kidney health for all New Zealanders.

Whakawhetai ki a koutou tou tautoko. Thank you all for your ongoing support.

Max Reid FNZIM
Chief Executive Officer





National Education Manager's Report

It's been a busy year with a variety of education sessions and resources given out to a wide variety of groups. The Chronic Kidney Disease Modules were completed, and information booklets have been printed and were sent out to all GP Practices throughout the country. Several education sessions using these resources were held throughout the country, including Chronic Kidney Disease workshops for staff at a large GP practice in New Plymouth (supported by Dr Ashak Hyat, the local nephrologist), and a workshop in Albany, Auckland for 40 Primary Health Nurses on the management of CKD in primary care. Further information forums and education sessions were also given to Primary Health Nurses in Tauranga, Ashburton and with University of Otago postgraduate nursing students. Feedback was very positive with Nurse Practitioners commenting on changing their practice following the sessions and feeling more confident making treatment decisions. One GP practice commented that these were the best education sessions they had had.

The review of KHNZ's Chronic Kidney Disease Management in General Practice - Summary Guide, which is distributed and used by most GPs in New Zealand, was completed and the updated Guides were distributed to all General Practices in NZ.

A new patient information brochure specifically for people newly diagnosed with Chronic Kidney Disease was completed and has proven to be very popular. This contains advice for patients on how to maintain their kidney function and manage their medication in times of sickness and was designed for General Practitioners to give to patients at the point at which they are diagnosed with CKD.

Visits to Rotorua and Dunedin Dialysis Units to update staff on our activities as well as speaking to a group in Kawerau about CKD and diabetes were well all received. Another successful Kidney Health Information Forum was held in Invercargill, and was well attended with positive feedback from the group.

Earlier this year I was fortunate enough to be invited by Dr John Collins and the Auckland CKD nurses to attend a day long workshop to understand more about the integration of renal care and Maori Healing. It was an excellent day.

The Mandarin version of KHNZ's audio-visual resources was completed and is now available on our website. Our suite now consists of versions in English, Samoan, Tongan and Chinese. A survey of Predialysis educators showed these audio-visually are well used and a valuable education tool for both staff and kidney patients and their families. A Te Reo version is currently being worked on.

I attended the Annual Renal Society of Australasia Conference in Sydney. This was a great opportunity for networking with other renal staff and keeping up to date with current practice. The annual RSA symposium in Auckland was held later in the year where I gave an update on the progress of the CKD primary care program and promoted our work.

It was a pleasure to be invited to be part of the Better Evidence and Translation in Chronic Kidney Disease (BEAT CKD) group. This group is keen to develop meaningful consumer engagement in research. The overall objective is to engage consumers in all aspects of planning, doing, disseminating and implementing CKD research. In doing so, consumer views, values and priorities should be reflected not only in the research undertaken but also clinical practice guidelines and health policy. Currently meetings are held by teleconference with our Australian counterparts as well as a subsequent BEAT CKD workshop in Adelaide.

My role continues on the Australia NZ Society of Nephrologists Dialysis Advisory Committee trying to ensure the NZ voice is heard. KHNZ has lead work to clarify the reciprocal agreement for dialysis treatment between Australia and New Zealand, and work on Key Performance Indicators continues.

The Ministry of Health is working with a wide and varied number of stakeholders to develop a Digital Health Strategy. I was invited to be part of this group, attending a meeting in November to discuss the strategy which describes a digital eco-system that creates the conditions that support delivery of the Ministry's Health Technology Vision and the NZ Health Strategy.

The National Renal Transplant Coordinators meeting in Auckland was a great networking opportunity and an opportunity to get an update on current practices. Given the number of calls to KHNZ's 0800-line relating to kidney donation and transplantation, this was a good chance to keep up to date.

The Home Dialysis conference was held in Auckland during the 2017/18 year. This is a bi annual event and was well attended. It had some inspirational speakers, including a panel with dialysis patients, and Kidney Health New Zealand had a stand there which proved popular. Finally, I'd like to thank the staff from the renal units throughout New Zealand for their continued support and encouragement.

Carmel Gregan-Ford
National Education Manager



Medical Advisor's Report

Dr Colin Hutchison

As we enter the final quarter of 2018 and look toward 2019 at Kidney Health NZ we see a mixed outlook for patients in New Zealand with chronic kidney disease under the new government. As with the majority of the public services, in healthcare we have anticipated the arrival of a new government with a positive outlook hoping to see the Labour government taking us towards increased funding for a skeletal healthcare system. However the investments to date in health care have been minimal and have left much of the sector widely disappointed. In their defence, the new government has had to face a number of major workforce challenges in particular the renewal of the Nursing and Resident Medical Officer contracts.

As the principal advocate for patients with kidney disease in New Zealand we are disappointed to so far see no increased investment into the management of chronic diseases within New Zealand. Although we were pleased to hear of the current government's intention to move away from the previous government's intense focus on easy to measure health targets towards a more rounded balance sheet addressing what is important to the health needs of the population, many months into the new administration we are still seeing a continued focus on the established, easy to measure targets such as elective volume and ED waiting times, rather than truly measuring the quality of the healthcare being provided to people with chronic diseases.

This said, New Zealand continues to perform well at the level of the local renal unit with the vast majority of the patients still receiving world class care once they hit end stage kidney disease and require dialysis or transplantation. However, one of the key gaps that seems to have been lost in transition from the old to the new government is implementation of the national Deceased Organ Donation Strategy signed off by government in mid-2017. This needs to remain a high priority for this government if it is not to be lost altogether. New Zealand remains behind the eight-ball in terms of deceased organ donation for comparable countries internationally.

In terms of dialysis programmes, New Zealand continues to out-perform many of our comparable countries around the World and remains an area which we should be proud of in New Zealand.

Our biggest concern at Kidney Health NZ remains the failure to detect and manage kidney disease early in a patient's journey, resulting in patients coming to unnecessary harm from preventable kidney disease, e.g. Diabetes or Hypertension. As your main advocates here in New Zealand we continue to petition government and the Ministry of Health for better investment into such long term conditions.



Demonstrating the value of Community Pharmacists educating the Hawke's Bay population, to temporarily discontinue medicines when they are unwell, to reduce the risk of acute kidney injury.

In Hawke's Bay a study is underway to:

1. Find out general practitioners and community pharmacists practice and views on patient education when prescribing, dispensing, or selling medicines with potential for contributing to community-acquired acute kidney injury. (Phase One)
2. Find out what proportion of the community are currently aware of which medicines they should stop during periods of acute illness. (Phase Two)
3. Pilot community pharmacists educating patients about stopping medicines during periods of acute illness. (Phase Three)

The first phase of this study occurred in 2015 and 2016. General practitioners (doctors) and community pharmacists working in Hawke's Bay were surveyed about patient education and the 'Triple whammy' combination of medicines. Thirty-seven doctors and 32 pharmacists did the survey, telling us that both professions felt they had the skills and knowledge to discuss with people the topic of medicine use during an acute illness, where there was a risk of dehydration and potential acute kidney injury risk. There was recognition that education on medicine use during acute illness was not always being given. Doctors expressed confidence in community pharmacists as medicine educators, and both generally supported both professions providing advice to people prescribed medicines which increased their risk of acute kidney injury during acute illness.

The 'Triple Whammy' is the combination of three types of medicines: ACE Inhibitor or Angiotensin receptor blocker plus a non-steroidal anti-inflammatory (NSAID) plus a diuretic. Doctors and community pharmacists had a similar approach to NSAID education regarding avoidance of self-medicated NSAIDs to avoid the 'Triple Whammy' combination. Doctors welcomed community pharmacists reminding them when a Triple Whammy combination was prescribed, and thought that community pharmacists currently tell people to temporarily withhold NSAIDs and ACE inhibitors when acutely unwell as part of standard care. This phase of the study is currently being written up for publication.

The Health and Disability Ethics Committee approved Phase Two and Three in 2017. All pharmacists in Hawke's Bay were invited to attend a talk by Dr Colin Hutchinson and Di Vicary before Phase Two began. Phase Two occurred in Hawke's Bay during July 2017 and February 2018, with people 18 years and older, invited to participate when they visited one of six volunteering community pharmacies to have a prescription dispensed for any long term medicine(s). The survey was developed with the assistance of Health Hawke's Bay PHO Maori advisor and members of the Hawke's Bay District Health Board Maori Health Team. One hundred thirty respondents completed the survey which asked four questions:

1. If you have excessive vomiting ('the spews') and/or diarrhoea ('the runs'), what do you do about taking your regular medicines?
2. Have you been told by a doctor, specialist, nurse, or pharmacist about what medicines you should stop taking when you have excessive vomiting ('the spews') and/or diarrhoea ('the runs')?
3. If yes, my medicines I would stop are.....

4. Please tick the medicines that you regularly take from the list below (NSAID, ACE Inhibitor, Angiotensin Receptor Blocker, diuretic, metformin).

Results are currently being analysed, ahead of publication.

Pharmacists working at four community pharmacies in Hawke's Bay participated in Phase Three between July 2017 and February 2018. Pharmacists were given with a specially developed educational resource pack including an online pharmacist course on acute kidney injury. One hundred and thirteen people prescribed a NSAID, ACE Inhibitor, Angiotensin Receptor Blocker, diuretic, or metformin received education by their community pharmacist. They were given information about:

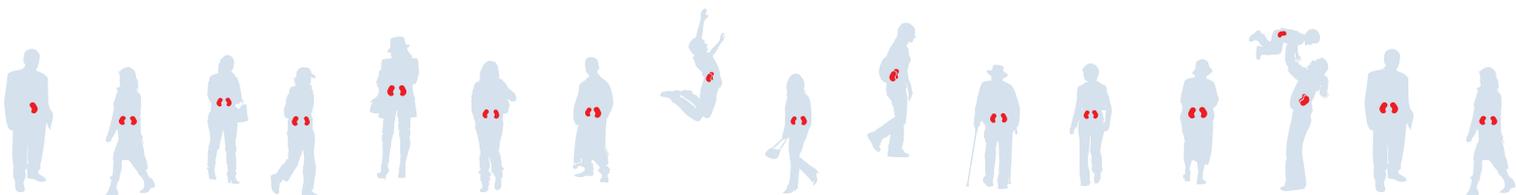
1. Which medicines to temporarily withhold during acute illness.
2. When to temporarily withhold these medicines (severe vomiting and / or diarrhea, or during infection (high fever, sweats, shaking)
3. Why to temporarily withhold some medicines in order to help their kidneys work the best they can when they are sick and a reminder to keep hydrated.
4. How long to temporarily withhold medicines for and when to ring the doctor or nurse.
5. When to restart their medicines when they are well again.

A Sick Day Guidance sheet that they could take home was also given to them. This sheet was developed after looking at resources overseas and with input from Health Hawke's Bay PHO Maori advisor and members of the Hawke's Bay District Health Board Maori Health Team. Kidney NZ provided the pictures.

During the first half of 2018, all Phase Three participants were telephoned by Di Vicary and invited to complete a follow-up interview. Ninety four people agreed and they were asked about:

1. Remembering the information their pharmacist gave them.
2. What would they now do with their medicines if they were acutely unwell with severe diarrhea and/or vomiting?
3. If acutely unwell, would they temporarily stop any medicines? If yes when would they ring the doctor or nurse, and when would they restart their medicines.
4. Did they have any feedback on the information or Sick Day Guidance Sheet?

Results are currently being analysed, ahead of publication.



**SUMMARY FINANCIAL STATEMENTS
FOR THE YEAR ENDED 31 MARCH 2018**

A full set of audited accounts is available upon request from Kidney Health New Zealand, PO Box 20072, Christchurch

SUMMARY STATEMENT OF FINANCIAL PERFORMANCE	2017/18 This Year	2016/17 Last Year
Income		
Bequests	\$100,414	\$1,000,000
Donations and Other Fundraising Income (Net)	\$21,302	\$193,262
Inneterst, Dividends & Other Investment Income (Net)	\$257,459	\$153,754
Other Income	\$10,000	\$46,100
Total Income	\$389,175	\$1,393,126
Expenditure		
Operating Expenses	\$307,284	\$301,081
Administrative Expenses	\$66,466	\$80,801
Total Expenditure	\$373,750	\$381,882
Net Surplus (Deficit) before Depreciation	\$15,425	\$1,011,244
Less Depreciation	\$2,493	\$3,670
Net Surplus	\$12,932	\$1,007,564
SUMMARY STATEMENT OF FINANCIAL POSITION		
Current Assets	\$66,153	\$95,506
Fixed Assets	\$1,136	\$3,629
Investments	\$3,235,387	\$3,188,455
Total Assets	\$3,302,676	\$3,287,590
Current Liabilities	\$36,693	\$34,529
Total Equity	\$3,265,983	\$3,253,051

ACKNOWLEDGEMENTS

Kidney Health New Zealand wishes to take this opportunity to thank the New Zealand Renal Units and the Consumer Council for their generous support during the year.

REMEMBRANCE DONATIONS

- Robert Ellis McLeod
- Roland Gordon Potter
- Norma Knowles
- Yick Hon Gee
- Lenin Vincent Mravicich
- Jeffrey Hamilton McKee
- Donald Moesbury Banks
- Albert Terence Waites
- John Stewart McIntrye
- Julie Box
- Barbara Eleanor Bird
- Kathryn Lilley
- Colin Bruce Thomas
- Robert Francis O'Connor
- John Watson
- John Winmill
- Joyce Angeleen Ware
- Pamela Wilson
- Jennie Lai Toi
- Dan Hartgill
- Adam Wratistlav

BEQUESTS

- Laurence Alexander McCool Estate

DONATIONS - \$500 AND OVER

- W G Johnston Charitable Trust \$4,907.82
- Anonymous \$1,000.00
- Anonymous \$1,000.00
- M Clayton \$500.00
- Naomi McLeish \$1,000.00
- Averil Langrell \$500.00
- Mercy Hospital Dunedin \$1,000.00

Yes, I want to help in the fight against kidney disease and support Kidney Health New Zealand!

I/we would like to donate: \$100 \$50 \$30 Other: _____

Payment type: Cheque (made payable to Kidney Health NZ) Mastercard Visa

Card number:

Card expiry date: / / Name on card: _____

I would like: A receipt for my donation Information about gifting to Kidney Health in my will

Information about kidney donation/transplants To become a member of Kidney Health NZ

Name: _____

Address: _____

Please return this form to Kidney Health New Zealand, PO Box 20072, Bishopdale, Christchurch.



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