

ANNUAL REPORT

2014-2015



P R E V E N T I O N • S U P P O R T • R E S E A R C H

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Chief Executive Officer
Max Reid

Medical Advisor
Dr Colin Hutchison

National Education Manager
Carmel Gregan-Ford

Office Administrator
Deanne Hock

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Charities Commission Number CC11348

Chairman's Report

Kia ora koutou katoa.

I always find this greeting so appropriate. The wish and blessing of health and well-being for all links directly to our name – Kidney Health New Zealand – and to our guiding principles which centre on the wellbeing of people affected by kidney disease – patients, families, whanau and of course the workforce which is so essential.

The past year has been very eventful, with major milestones being the retirement of our long-serving key staff person Guy Johnson and our Medical Director Kelvin Lynn, and the appointment of Max Reid as Chief Executive and Dr Colin Hutchison as Medical Advisor.

Guy's role was crucial for KHNZ. He guided the organisation and kept it strong through very many changes, and consistently helped it grow both in strength and in the national and international recognition of its role. We are very aware that in a not-for-profit organisation the volunteer board members are elected and over time they retire, having made their contribution, but the success of an organisation like KHNZ is very dependent on the continuity, the energy and the perspective that is brought by the permanent lead staff person.

Similarly Kelvin provided KHNZ with advice and guidance from a medical perspective, based on his many years as a physician and as a participant in the governance and management of health services. Kelvin built and strengthened relationships even as the practices of both government and the profession evolved, bringing KHNZ to the point where we have a recognised role in contributing to national policies and to system-wide planning.

Now we have Max Reid, who has taken the reins and is running with the many opportunities that arise from recognition of a national organisation that makes consistently useful input on issues, whether they arise in relation to local services or in national for a like the National Renal Advisory Board. Max has joined our much-valued Education Officer Carmel Gregan-Ford and Administrator Deanne Hock. The three staff have quickly established us in a new office in Christchurch.

Supporting Max and also the Board we have Colin Hutchison who has quickly become active in our work, bringing the twin perspectives of a renal medicine professional and a team leader from a regional centre.

After much work we have now updated our Strategic Plan and out of that our Annual Plan, with a clearer set of priorities for work both by the staff and the Board. We are in good financial shape and as we move forward we can do so with greater confidence that we are focused on what most needs to be done for patients and families, for people with early stages of kidney disease, for more affordable health system support, and for increased transplantation rates.

Increased transplantation of live-donor kidneys as well as deceased-donor organs has been a major focus for us in the past year and will continue to be so in the foreseeable future. As the risks of operations are reduced the potential benefits have become clearer; greater life expectancy and quality of life for patients, linked benefits for families, and greatly reduced costs for the health system and the New Zealand taxpayer. What's not to like?!

I'd like to acknowledge the continued volunteer commitment of our Board members; our Treasurer Richard Robson, Michael Papesch, Humphry Rolleston and Nora Van der Schrieck, and Nick Polaschek who joined us in the past year, shortly after his retirement from the Health Ministry. Nick is already contributing so much based on his experience in renal services, system management and policy formulation.

Our annual report has information about our many activities, but I recommend readers to our website where there are regular updates, contact details for any inquiries from anywhere in the country, and a wealth of resources for patients, families and medical professionals. We are proud of the work that has gone into these, and acknowledge the support we have received from volunteers and from the Health Ministry in creating them and making them available nationally.

Dave Henderson
Board Chairman



CEO's Report

Having only joined the Kidney Health NZ team in early February, reviewing a year only two months of which I participated in, presents something of a challenge. At least my views on the organisation's performance for the year ended 31 March 2015 will be objective!

As one of Kidney Health NZ's two 'newbies' – the other being our new Medical Advisor, Dr Colin Hutchison – it is worth outlining the rationale for restructuring the team upon previous Medical Director Prof. Kelvin Lynn's and previous Executive Director Guy Johnson's retirements in late 2014. The move towards establishing an expanded Chief Executive Officer role, and a Medical Advisor position (with decreased hours compared with the Medical Director's role it replaces) reflects Kidney Health NZ's desire to better position itself as the national advocate for people with kidney disease, their families and others who support them. Over recent years, the Ministry of Health has increased its investment in clinical oversight and support for the renal sector. This has seen, for example, the establishment of Live Kidney Donation Aotearoa (a national project contracted to Counties-Manukau DHB) and a National Renal Transplant Service. These organisations work alongside Organ Donation NZ and the Ministry's existing National Renal Advisory Board.

The organisation's restructuring of key roles re-positions Kidney Health NZ as a key national voice in this mix – and clearly reflects the priorities of the Board's 2014-2017 Strategic Plan, setting out KHNZ's intent to:

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

Carmel Gregan-Ford, our National Education Manager, refers in her report to the 15% increase in calls to Kidney Health NZ's 0800 number, and the launch of our DVD-based education resource. Both point to the significant

role Kidney Health NZ continues to play in providing support to renal patients and those who care for them. Indeed, such was the demand for the DVD resource that the initial production run had been fully distributed within three months of its launch, with a further run having since been produced.

Kidney Health NZ has continued to provide education and support for patients and their families throughout New Zealand – matching our resources to the varying needs of local support groups and societies. Kidney Health NZ's ongoing financial contribution towards the work of the Auckland District Kidney Society has also been maintained. Whilst, for various reasons, Kidney Health NZ's Consumer Council – established in February 2014 – did not meet during the 2015 financial year, a further meeting of the Council is planned for September 2015, along with an intention (expressed in the Operational Plan), for the Council to meet at least annually.

Our commitment to health professional education and political advocacy has also continued, increasing in proportion to Kidney Health NZ's national profile. Alongside the education forums offered throughout the country to both patients and health professionals, a growing proportion of the calls to the 0800 helpline are also from community-based health professionals. This growing engagement with health professionals in the primary health setting reflects an increasing awareness on the role primary healthcare professionals have to play in both the prevention and early identification of chronic kidney disease. Kidney Health NZ has been actively involved in the development of the Ministry of Health's Chronic Kidney Disease Consensus Statement, released in March 2015, and will continue to play a significant role in the subsequent primary healthcare initiative that the Ministry has launched on the basis of the Consensus Statement.

At a political level, a well-researched Kidney Health 'Manifesto' was produced and distributed to each party's political spokesperson ahead of the 2014 General Election. Available on the Kidney Health NZ website, this document (and the kidney health priorities it identifies) has provided a valuable starting point for subsequent discussions with a number of political leaders, and with the Ministry itself. More recently, Kidney Health NZ has encouraged and enabled cross-party support for a Private Member's Bill seeking to raise significantly the level of financial support available to live organ donors.

In the year ahead Kidney Health NZ will continue to pursue its strategic goals – maintaining a strong media presence, providing strong and well-researched advocacy at both local and national levels, while continuing its well-established and much-valued support for health professionals, individual kidney patients, their families, and the various kidney support groups across NZ. We do so in the knowledge that all this work is only possible through the financial generosity of those we support, that of their friends and family, and the financial support of those who have gone before.

Finally – but no less importantly – let me express my thanks to the rest of the KHNZ team. To my Christchurch colleagues Carmel Gregan-Ford and Deanne Hock for their dedication and commitment; to Dr Colin Hutchison for the valuable contribution he is already making to Kidney Health NZ's direction and profile; and to Dave Henderson and the KHNZ board for their ongoing support, guidance and governance of the vital work that Kidney Health NZ is committed to.

Tēnā rawa atu koutou katoa.

Max Reid
Chief Executive Officer



Launch of DVD Resource

National Education Manager's Report

Kidney Health NZ's 'by-line' is Prevention - Support - Research. 2015 has been another busy year fulfilling the organisation's aims across these three areas.

In September Kidney Health NZ was invited by the Hawkes Bay District Health Board to participate in a Hawkes Bay Health Forum – "Love your Kidneys". It was a full-on two days with Medical Director Kelvin Lynn and I talking to a variety of groups about kidney disease, its impact and what can be done to try and decrease the numbers with chronic kidney disease. There was a large turnout for each of the sessions, with medical professionals (including GPs, Practice Nurses and pharmacists) attending the evening sessions, and patients and their families attending the daytime sessions. We estimate that we spoke to around 300 people over the two days.

In January we had a great start to start the New Year when we were fortunate enough to be able to spend time with Ros and Hugh Cole-Baker during their stopover in Christchurch, a group of us cycled around Hagley Park on the first day of the year together with the Walking for Kidneys duo. Ros and Hugh walked the length of New Zealand to raise awareness about live kidney donation. Ros had donated her kidney to Hugh only 8 months before setting off. Their journey created a lot of publicity, including television and newspaper interviews, both locally and nationally.

We moved into our own office space in February this year. Located in Christchurch's busy Bishopdale shopping centre, it has the benefit of plenty of parking, and the new signage is eye catching, leaving no doubt as to our role.

In February I attended my first meeting of the Australasian Home Dialysis Advisory Committee in Melbourne. The group meets face to face twice a year and via teleconference twice a year. At this meeting it was decided that the biannual Australasian Home Dialysis Conference will be held in Auckland in 2018, and KHNZ is looking forward to being part of the organising committee.

As a council member of the Agencies for Nutrition Action (ANA) I have attended three meetings over the last year. This is a great opportunity to network with other organisations and keep up to date with the latest projects, news and activities in the fight against obesity and focus on healthy lifestyles.

In March I was excited to finally see our biggest project recently – our audio-visual information resource – officially launched at a function hosted by the Minister of Health, Dr Jonathan Coleman, at Bowen House in Wellington on World Kidney Day. This also coincided with the launch of the Ministry of Health's Chronic Kidney Disease Consensus Statement. The DVD resource is a totally New Zealand production, making it one of the first designed specifically for people living in New Zealand with kidney disease.

Tongan, Samoan and English versions are now available on our website, YouTube and on data sticks. The data sticks (styled to look like a credit card) have been distributed to renal units and patient support groups nationally. They have proved both incredibly popular and very versatile. In some regions, for example, the resources are being used to show medical students as part of their introduction to renal medicine. Requests for the resource continue to flow in, and the Tongan and Samoan versions also produced have been sent to a variety of Pacifica Health organisations. We have even had enquiries from overseas requesting use of the resource – a real testament to its value as an education tool.

Our special thanks to Murray Fergusson from Clearcut Productions, who went the extra mile with his dedication and commitment to this project to ensure a high quality resource was produced. Also a big thank you to the staff and patients from the Wellington Renal Service at Capital Coast District Health Board, who were

involved in the filming. Your participation is very much appreciated. The series of DVDs can be found on our website at <http://www.kidneys.co.nz/Patient-Information/Audiovisual-education-resources/>

As well as completing these resources we also released a Know your Kidney Numbers information sheet, which has also proved to be very popular. Plans are underway to add further to these resources in the coming year.

Our website continues to be well utilised, with many calls and emails coming as a result of people viewing the site. We are committed to keeping the website as up to date as possible, along with our Facebook Page which I update as frequently as possible. Alongside these popular social media, our 0800 helpline has also experienced an increase in growth, with a 15% increase in calls from previous years.

Carmel Gregan-Ford
National Education Manager



Medical Advisor's Report

I joined Kidney Health NZ in April 2015 as Medical Advisor, having previously been involved in an informal capacity. Following a period of getting to know the team and the objectives of KHNZ we are now busy with a number of new activities.

Of particular importance in the year ahead will be the work Kidney Health NZ will be involved with supporting the roll out of the new national CKD consensus guidelines. KHNZ will provide a crucial role in the education around these guidelines to primary care working closely with the Ministry of Health and other organisations involved in their development.

Max Reid and I have recently been working together to collate responses from an Official Information Act request to all District Health Boards, via which we are endeavouring to get

a clearer understanding of the current staffing of DHB renal units across the country, and their strategies for providing dialysis care going forward.

To help meet the Kidney Health NZ strategic objective of supporting the ongoing development of transplantation in NZ we are also currently designing a public survey assessing attitudes to organ donation in NZ.

Since mid-2015 we have begun the process of commissioning a new set of Patient Information Sheets to complement the patient resources already available through Kidney Health NZ.

Dr Colin Hutchison
Medical Advisor



The Home First Study Research Report

Each year, Kidney Health NZ makes a limited amount of grant funding available to support innovative research in the area of Kidney Health. This year, grant funding support was made available to Rachael Walker, a Nurse Practitioner with Hawkes Bay DHB. Rachael reports on her research project below:

The number of patients on dialysis in NZ is increasing at a 10-fold higher rate than the general population. Home dialysis is associated with improved survival, better quality of life and reduced cost compared to facility dialysis, yet the number of patients choosing home dialysis in NZ is diminishing. To date, we do not understand from the patient and their families perspective the factors which influence their choice of treatment and the barriers to home dialysis.

Although there has been previous research into this area, there has not been any research in NZ and internationally there have only been limited studies that explore the patients and families views on what influences their decision about which treatment they choose. Research into patients and caregivers perspectives of the factors which influence their choice of renal replacement therapy treatment will help renal services to develop policy and practice which better aligns to the needs of patients.

The Home First study which aims to explore these areas forms the basis of my PhD, which I am currently undertaking through The University of Sydney. I am currently two years into my PhD and have been very fortunate to receive a number of grants to support my research, one of which is from Kidney Health New Zealand.

This grant has enabled me to interview patients and their caregivers about their experience of choosing dialysis.

With the assistance of three renal units in New Zealand, and my research team, I have completed fifty-two patient and caregiver interviews and am currently writing up my findings from these interviews. These findings will help us to better understand patients and family perspectives of the barriers to home dialysis. The next step in our research is to use these findings to develop surveys for patients and family members which explore in more detail the barriers to home dialysis.

We aim to have completed this research by the end of 2016 and hope it will help clinicians and policy makers to better align services to the needs of the patients and their families.

Contact details: rachael.walker@hbdhb.govt.nz

A big thank you to KHNZ for helping to support this research.

Rachael Walker
Nurse Practitioner



Summary Financial Statements for the year ended 31 March 2015

A full set of audited accounts is available upon request from Kidney Health New Zealand, PO Box 20-072, Christchurch

Summary Statement of Financial Performance for the year ended 31 March 2015	2014/15 This Year	2013/14 Last Year
Income		
Bequests	291,575	97,226
Donations	40,893	33,890
Telemarketing (Net)	95,718	91,657
Investment income (Net)	165,022	181,030
Other Income	20,000	-
Total Income	613,208	403,803
Expenditure		
Operating Expenses	173,081	150,092
Administrative Expenses	131,288	187,815
Total Expenditure	304,369	337,907
Net Surplus before Depreciation	308,839	65,896
Less Depreciation	1,509	2,275
Net Surplus	307,330	63,621

Summary Statement of Financial Position for the year ended 31 March 2015

Current Assests	624,015	450,453
Fixed Assests	7,624	1,352
Investments	1,749,258	1,613,657
Total Assests	2,380,897	2065,462
Current Liabilities	52,821	44,716
Total Equity	2,328,076	2,020,746

Acknowledgements

Kidney Health New Zealand wishes to take this opportunity to thank the following for their generous support during the year; **New Zealand Renal Units, members of the Kidney Health NZ Consumer Council, Murray Ferguson (Clearcut Productions).**

Remembrance Donations

Wayne Roberts, Ross Owen Stokes, Michael Molloy, Anthony Ignatius McNally, Raymond Beach, Alan Douglas Pullar, Athol Thomas Pearson, Lesley Gideon, Ramu Patel, Colleen Bolt, Audrey Tilson Rosalie Ann Munn, Garry Wayne O'Sullivan, Lyndsay Noeline Dunshea, Norman Jones, Robert Anthony Levien.

Donations \$500 and Over

Your donations help us help others.

New Zealand Mortgages & Securities
\$10,000.00

Powerhouse Civil Ltd \$500.00

Commercial Consultants (PN) Ltd \$2,000.00

Lottery Grants Board \$23,000.00

D D & G Kalidas \$2,000.00

W G Johnston Charitable Trust \$5,817.14

K & C Tempest \$1,000.00

McGhie Family Trust \$500.00

Lance Tavinor \$4,665.00

Bequests

Estate Dorothy McCarthy

Estate David Chillas Henderson

Supporting Kidney Health New Zealand

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

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

Thank you for your support.

 **Kidney Health**
NEW ZEALAND