Bioney Health NEW ZEALAND

ANNUAL REPORT

FOR THE YEAR ENDED 31 MARCH 2017

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Chairman's Report

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Dr Colin Hutchison (Hawkes Bay)

National Education Manager Carmel Gregan-Ford (Christchurch)

Administrator Deanne Hock (Christchurch)

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Phone 0800 KIDNEYS (543 639) Email info@kidneys.co.nz Website: www.kidneys.co.nz Find us on Facebook: Kidney Health New Zealand This has been a great year for Kidney Health New Zealand, and I'm proud to have been a part of the achievements we have made. Looking back at the aspirations and hopes we had when we put together our Strategic Plan 2014 - 2017, I see we have been remarkably successful. Issues we identified as a Board, and issues we heard from our Consumer Council, came together in a Plan that expressed a lot about the role we hoped to play and the changes we hoped to achieve in making life better, and easier, for kidney patients and families.

We live in a landmark time. A tide has turned and public recognition of the issues that face patients and families is greater than ever before. A key milestone was the passing by Parliament of measures to drastically improve support for living kidney donors, including full reimbursement of costs and of lost income, to be covered as of right through the Ministry of Health. After years of work especially by people connected to KHNZ, the Bill to put these measures in place was supported by all political parties, at every stage of the parliamentary process. When our CEO Max Reid and I presented our case at Parliamentary Select Committee, the unanimity of MP's support was so unusual as to be truly remarkable. You can read more detail of this and other achievements in the reports of our staff.

For his work on this and in very many other areas I want to warmly thank Max. His huge commitment has ensured so many of the aspirations expressed in our Plan have either come to fruition or are

well on the way. Particular thanks also to Carmel Gregan-Ford our Education Manager and Colin Hutchison our Medical Advisor. These three lead staff have conveyed our perspective into so many and varied forums around the country. KHNZ has gained very significantly in terms of respect for the insight and expertise we bring to the table.

I also want to thank the members of our Board, each of whom has contributed valuable insight from their different perspective so that as a whole we fulfil the role of visioning, planning and governance. As a volunteer Board we recognise we are all there to serve KHNZ - not our various background organisations, and that is important for an organisation addressing issues on a holistic national level.

Finally I want to express my thanks to the participants in our Consumer Council and to the respondents to our survey. Your input has helped us immensely both in shaping our priorities and in providing us with real examples of how services can be improved. Your stories, anonymous of course, have given us real evidence to give to government and its agencies and thus have helped us bring about real change. We are about to begin work on a new strategic plan and issues you have raised which are not yet resolved, such as access to dialysis away from home, will be part of that. We look forward to continuing to work with you in the future.

Dave Henderson Board Chairman



World Kidney Day Round The Bays Runners



Chief Executive's Report

Kia ora tatou katoa

This year marks the conclusion of Kidney Health New Zealand's 2014-17 Strategic Plan. I would therefore like to take this opportunity to report, not only on some of the achievements of the year to 31 March 2017, but also on the significant progress that the organisation has made against the wider priorities it set in that three year Strategic Plan.

Developed by the Board of Kidney Health New Zealand (KHNZ) following extensive consultation with regional patient support groups, the Strategic Plan laid out a vision of 'Better Kidney Health for all New Zealanders.' To that end, the plan identified three overarching goals:

- 1. To be the national voice for people with kidney disease and their families.
- 2. To be a primary source of reliable and relevant information on the prevention and management of kidney disease.
- 3. To commission research to support KHNZ's objectives.

In a review of the Strategic Plan in 2015, a fourth Goal was added:

4. To be a leading advocate for world class kidney health care in New Zealand

Advocacy has been an important dimension to the voice that KHNZ has endeavoured to articulate on behalf of renal patients and their families. At a national level KHNZ – with strong input from our Consumer Council – has placed before two Ministers of Health and the various other parties' health spokespeople, a pre-election 'Manifesto' ahead of the last two General Elections. In the 2014 Manifesto, KHNZ identified seven priorities for improving kidney health in New Zealand:

- 1. Addressing New Zealand's internationally low rate of deceased renal transplantation.
- 2. Facilitating pre-emptive live kidney transplants.
- 3. Increased reimbursement of lost income for live donors.
- 4. Reducing barriers to home dialysis.
- 5. Improving support for home dialysis patients.
- Improving access to 'away from home' dialysis for haemodialysis for patients needing to travel for work or family reasons.
- Improving General Practitioners' knowledge of how to identify and best manage Chronic Kidney Disease in the primary healthcare setting.

It is encouraging to report that significant progress has been made against most of these – a reflection of the organisation's commitment to not only raise these issues in the political arena, but to develop the level of relationship with MPs across the political spectrum required to ensure such progress is made.

KHNZ has also worked with a number of District Health Boards, advocating on issues of concern raised by local kidney support groups and societies.

KHNZ also continues to be a reliable source of information, not only for renal patients and their families, but also increasingly for other health professionals in the primary health setting, as they too seek to support renal patients in their care. KHNZ's extensive range of brochures continues to be reviewed and expanded according to demand, and the series of educational videos released on our website and available in USB format from pre-dialysis educators have been extremely well-received by newly diagnosed renal patients and renal educators alike. Initially produced in English, Samoan and Tongan, in the last year – at the request of the Chinese community – a Mandarin translation has been produced, and a Māori translation is currently being undertaken. Carmel is also responsible for producing KHNZ's quarterly newsletter, managing the organisation's Facebook page (with more than 600

followers) and responding to the more than 800 calls per annum to KHNZ's 24/7 0800 helpline.

Alongside this has been the exceptional work that continues to be undertaken by Carmel Gregan-Ford, KHNZ's National Education Manager. In addition to the regular invitations for educational sessions that Carmel receives from local kidney support groups and societies, she has effectively lead KHNZ's involvement in the Ministry of Health's initiative to raise awareness of Chronic Kidney Disease amongst GPs and other healthcare professionals working in the primary health setting. Carmel has developed a series of training modules and has coordinated the delivery of these across New Zealand.

Increasingly – and particularly over the past year – KHNZ has developed a strong working relationship with the Ministry of Health, contributing to a number of key initiatives. In addition to our involvement in the Ministry's CKD project (noted above) KHNZ also played a key role in the successful passage of legislation increasing the financial support available to live organ donors to 100% of lost income for up to twelve weeks post-surgery – including researching (at the request of the Ministry) the experience of previous live kidney donors of the former financial support regime. I have also had the opportunity to represent kidney health consumers on the Expert Advisory Group that produced earlier this a National Strategy for Deceased Organ Donation, and I am currently a member of the Ministry's Advisory Group developing processes and protocols for the new compensation regime for live organ donors. That KHNZ is now perceived as a trusted partner by the Ministry represents a significant step forward.

As much has been achieved by KHNZ in the past year and against the organisation's Strategic Plan, there is still much to do. We remain committed to seeing an increase in the proportion of patients with advanced Chronic Kidney Disease receive a transplant as their first-line treatment, and for the increasing number of patients requiring dialysis to be both encouraged and supported to dialyse at home where this is deemed appropriate to their needs. We remain concerned at the variability of some renal services across the country – that urban and rural patients do not always receive equivalent support, and that our Māori and Pacific populations not only bear a disproportionate share of the burden of kidney disease, but are also significantly less likely to access the treatment and support they need as compared with the general population.

As the Kidney Health New Zealand Board now looks ahead to the development of a further Strategic Plan, these issues will remain front and centre in our thinking. In the meantime, this Annual Report and our Annual General Meeting give us all an opportunity to celebrate the significant achievements of the past year and to commend those who have lead and supported them. To my colleagues on the KHNZ staff - Carmel Gregan-Ford, Deanne Hock (our Administrator) and Dr Colin Hutchison (our Hawkes Bay-based Medical Advisor - my most sincere thanks for your ongoing contribution and commitment. Nearly three years on in the role of Chief Executive Officer, I still feel like the new kid on the block, and realise how much I still have to learn about kidney disease and its impact on patients and their families. The accumulated knowledge and experience that Carmel, Deanne and Colin bring to the team represents, for me, an invaluable support. As has been the role that KHNZ's equally committed Board members continue to play guiding the organisation's strategic direction, testing the ideas that Colin and I bring to the Board table, and reminding us that the reason we do this is for the benefit of patients, families, and the wider community.

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

Max Reid FNZIM Chief Executive Officer



National Education Manager's Report

Chronic Kidney Disease Education

The Management of Chronic Kidney Disease (CKD) in Primary Care education program has taken up a fair chunk of time this year, with work continuing on the accompanying education materials designed to complement the program. We continue to work alongside the Best Practice Advocacy Centre (BPAC) as they continue to launch their electronic tool designed to assist GPs in identifying at risk patients in their practices. Both projects are aimed to reduce the numbers of patients reaching end stage kidney disease by slowing down the progression of kidney disease.

1200 information packs were distributed to General Practices throughout New Zealand. In the packs were: CKD Programme Information booklet, Resource order form, letters to GP and Practice Manager, a sample of four of our brochures. The CKD Management in General Practice – Summary Guide was reviewed and updated and is being distributed throughout NZ.

Already there has been several education sessions provided using the new modules these include the Primary Care Nurses conference in Timaru, the Renal Society of Australasia in Auckland, GPs and practice nurses in Whanganui, Palmerston North and Nelson, and others with many more booked in. We are currently working on a Chronic Kidney Disease guide for people newly diagnosed with CKD for GPs to distribute as needed. I would like to acknowledge Dr John Collins, Dr Waala Saweirs, and Nurse Specialists Chrissy Taylor, Sandy Speedy, Miranda Walker and Kay McLaughlin for their support, expertise and commitment to enable this project to be completed.

We are on our third run of the audio visual resources which continue to be requested and well used. The review of these resources done via Survey Monkey was very positive; it is considered a very useful tool in the education of kidney patients and their families and staff new to renal nursing. These resources are now available in Samoan, Tongan, Mandarin, English, with a Māori version in production. We received a letter from the Canterbury and Hawkes Bay District Health Boards thanking us for the resources, which they have found invaluable as part of their predialysis education program, including very positive feedback from patients.

KHNZ Consumer Council

In March we held our third meeting with our Consumer Council with 20 people attending. This continues to be a valuable group with a variety of discussions about issues for renal patients and their families. At this meeting five of the most important current issues, were identified and voted for by the group, as priority for the Manifesto to be presented to the MPs later in the year prior to the general election, these included;

- 1. Deceased organ donation
- 2. Advocate for the funding Tolvaptan (for Polycystic Kidney Disease)

- 3. Accessibility to dialysis at other renal units in NZ
- 4. Including renal as part of the Ministry of Health's long term conditions work programme
- 5. Funding levels of the health system overall

World Kidney Day

World Kidney Day was March 9th 2017; the theme was Obesity and CKD. The renal units around the country decided to do their own thing regarding raising awareness this year. A letter to Members of Parliament was written asking them to help make Chronic Kidney Disease more prominent on the health and policy agenda in New Zealand, as part of the WKD campaign.

Website and 0800 Help Line

Both the website and free phone line continue to be well utilised with in excess of 850 calls in the last year, and hundreds of emails. The Facebook page is becoming more popular and our recent foray into Twitter is a work in progress.

Dialysis Advisory Committee-ANZSN (Australia New Zealand Society of Nephrology)

As a member of the ANZSN we meet four times a year either face to face or by teleconference. Although this tends to have an Australian focus, David Semple (an Auckland based nephrologist) and I work to ensure NZ is represented. This year saw a focus on developing Key Performance Indicators for dialysis units, electrical compliance standards for dialysis machines, and developing a national consent form template for dialysis patients. Government advocacy issues have also included working on the reciprocal agreement for free dialysis treatment between Australia and New Zealand. Having representation from NZ on this group remains imperative as we remind our Australian counterparts of the great work being done here.

Carmel Gregan-Ford National Education Manager



KHNZ Funded Research

Patricia Metcalf

Prevalence of chronic kidney disease in a large primary care cohort.

VIEW investigators at the University of Auckland (Dr Patricia Metcalf, Professor Rod Jackson, Associate Professor Sue Wells) and Associate Professor John Collins, a nephrologist from Auckland City Hospital and the University of Auckland collaborated to determine the prevalence of Chronic Kidney Disease in the Auckland population. VIEW investigators use the PREDICT web-based computerised decision support tool that is used during primary care patient consultations to estimate a patient's five-year risk of cardiovascular disease and management advice. The ever-growing cohort is then annually linked via encrypted national health index (NHI) numbers to routine national databases that include medication dispensing, laboratory testing, primary health organisation (PHO) enrolments, hospitalisations and deaths.

The prevalence of Chronic Kidney Disease or reduced renal function is unknown in the general population of New Zealand. We used clinical data from 129,635 patients aged 35 to 79 years from the PREDICT cohort collected between January 1, 2010 and August 15, 2015. Prevalence of Chronic Kidney Disease was calculated by gender, age, ethnicity and socioeconomic status quintiles. In this population of people having a cardiovascular disease risk assessment in primary care, the overall prevalence of CKD was 5.4% with no difference by gender. The relative risks of Chronic Kidney Disease dramatically increased with age and compared to Europeans and Others were 2.7 times higher in Pacific, 1.9 times higher in Māori and 1.3 times higher in Indian patients, but were not significantly different in Other Asians. Compared to the highest socioeconomic group quintile the relative risks were 1.1 for quintile 2, 1.2 for quintile 3, 1.3 for quintile 4, and 1.5 for quintile 5 (the lowest socioeconomic group).

In conclusion, knowledge of the risk factors for CKD in a New Zealand population that include a higher prevalence in higher age groups, people of Pacific, Māori and Indian ethnicities and people in higher deprivation groups, suggest public health priority groups that should be targeted for reduction of this disorder.



Medical Advisor's Report

Dr Colin Hutchison

This year has seen Kidney Health New Zealand continue to work in collaboration with Renal Units in New Zealand to ensure all patients have equitable access to world class kidney care. One of our key pieces of work this year has been to commission the development of Key Performance Indicators (KPI) for the care of patients with kidney disease in New Zealand.

We are undertaking this work in collaboration with the Ministry of Health and the National Renal Advisory Board. The aim of the KPIs is to drive service improvement and increase efficiency and consistency of patient centered care through the transparent comparison of DHB performances in both primary and secondary care.

These KPIs of the DHBs of New Zealand are focused on the patient journey through the renal unit. They are independent of, and are not designed to replace any current or future targets of clinical care used by the renal teams of New Zealand.

The KPIs are divided into two broad groups to reflect the patients journey within primary and secondary care.

Primary Care KPIs:

- 1. All GP practices will develop and maintain a registry of patients with CKD.
- 2. GP practices will undertake targeted screening and monitoring of groups at high risk of CKD.
- 3. Eighty percent of patients with CKD will have blood pressure within target range: blood pressure is 140/90 or less without proteinuria or 130/80 or less with proteinuria.
- 4. Ninety percent of patients will have their kidney risk explained.
- 5. Patients with advanced CKD (stages 4+5) within New Zealand will have timely access to specialist care at a local renal unit.

Secondary Care (Renal Unit) KPIs:

- Greater than 90% of patients starting a renal replacement therapy, from Chronic Kidney Disease, will have been referred to a renal service at least 3 months before treatment is commenced.
- 2. All patients with advanced CKD, stage 4 and 5, known to a renal service will be cared for by a renal MDT.
- 3. Within 90 days of first specialist appointment with the renal service all patients, under 75 years of age, with Chronic Kidney Disease stage 4 or 5 will have a decision made as suitable for transplant assessment or not. The patient will be informed of this decision (using local documentation).
- 4. Greater than 80% of patients starting planned dialysis for progressive Chronic Kidney Disease will start dialysis with definitive access.
- 5. All patients receiving dialysis will be offered Advanced Care Planning.

Other Activities:

In addition, to the development of these KPIs we have continued to work alongside renal services to ensure that barriers to effective patient care are removed. Key activities have included the development of educational talks for primary care, lobbying Pharmac for new treatments for patients with kidney disease and the development of a secure website for renal teams to share protocols for the care of renal patients.

Looking ahead, we see 2018 being a key year to keep the care of patients with renal diseases high on the priorities of both the Ministry of Health and individual DHBs.

SUMMARY FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 MARCH 2017

A full set of audited accounts is available upon request from Kidney Health

New Zealand, PO Box 20072, Christchurch

SUMMARY STATEMENT OF FINANCIAL PERFORMANCE	2016/17 This Year	2015/16 Last Year
Income		
Bequests	\$1,000,000	\$7,788
Donations	\$125,984	\$31,648
Telemarketing (Net)	\$67,278	\$81,196
Investment Income (Net)	\$153,754	\$157,239
Other Income	\$34,895	\$25,000
Total Income	\$1,381,911	\$302,871
Expenditure		
Operating Expenses	\$289,876	\$295,755
Administrative Expenses	\$80,801	\$80,975
Total Expenditure	\$370,677	\$376,730
Net Surplus before Depreciation	\$1,011,234	(\$73,859)
Less Depreciation	\$3,670	\$3,225
Net Surplus	\$1,007,564	(\$77,084)
SUMMARY STATEMENT OF FINANCIAL POSITION		
Current Assets	\$546,034	\$279,177
Fixed Assets	\$3,629	\$7,299
Investments	\$2,737,916	\$2,000,852
Total Assets	\$3,287,579	\$2,287,328
Current Liabilities	\$34,528	\$39,635
Total Equity	\$3,253,051	\$2,247,693

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

Kidney Health New Zealand Consumer Council Dr John Collins

REMEMBRANCE DONATIONS

Kirsty Anne Grainger Gloria Watene Dinny van Engelen Robin Alfred Day Atalia Justina Vulu Trevor Kenyon Court Valma Caron Elizabeth Watkins Roselynne Mitchell Hugh Chan Barry O'Sullivan Ravi Shankar Mangar

BEQUESTS

Anonymous Bequest

DONATIONS - \$500 AND OVER

W.G. Johnston Charitable Trust	\$5,239.90
Des & Olive Walker Charitable Trust	\$100,000.00
Russell Watson	\$500.00
Mercy Hospital Dunedin	\$1,000.00
Averil Langrell	\$500.00
Liz Carrick	\$1,935.00
Laurence A. McCool	\$1,000.00
Helen Rouse	\$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.

ph: 0800 KIDNEY (0800 543 639) e: info@kidneys.co.nz www.kidneys.co.nz

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