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 six strategic goals:

1. National Awareness: KHNZ extends its reach so we are positively impacting everyone affected by, or at risk of, kidney disease.
2. Information and Support: KHNZ is recognised nationally as the primary source of information on the prevention and management of kidney disease.
3. Sustainability: KHNZ is financially strong and structured for financial growth.
4. Advocacy: KHNZ is recognised as an influential voice and the national advocate for people affected by, or at risk of, kidney disease.
5. Leading and Collaborating: KHNZ collaborates with stakeholders on bilateral initiatives and provides national leadership to support local kidney groups and societies to achieve their objectives.
6. Service Delivery: KHNZ delivers, subject to funding, products and services that promote better kidney health and support for those affected by, or at risk of, kidney disease to live full lives.

Over the 2018/19 year, the Board’s focus has been on positioning KHNZ to continue to grow and succeed into the future. Four issues stand out in 2018/19:

First, the Board finalised a new strategic plan for KHNZ to shape the direction of KHNZ to 2024. The six strategic goals of the Strategic Plan are summarised above. For the next five years, and subject to funding being secured, we see an opportunity for KHNZ to move progressively to providing national services to kidney patients and their families, over and above the information and support that we provide now. These would sit alongside, and not overlap or duplicate, the critical services provided to regional groups and societies. To do this, we will also need to strengthen our engagement and collaboration with regional groups and societies. Delivering on this potential will be a key area of focus for the Board over 2019/20 and beyond.

Second, the new, modern constitution for KHNZ at the AGM in 2018 also introduced the possible option that over a period of time, a Board member can serve. In 2018/19, we saw the retirement of long-standing Board members Nora van der Shrieke, Dave Henderson and Humphrey Rolleston. At the November 2019 AGM, Richard Robson will also step down from the Board. All four have been excellent servants of kidney 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.

The retiring Board members have been replaced by John Kearns, Traci Stanbury, David Shearer and Natalie Brown. All four joined the Board in November 2018 and have been energetic and enthusiastic Board members. They will be joined by Christine Prince in November 2019 (to succeed Richard Robson), and will work alongside Nick Polaschek and I for the forthcoming year. I am confident that this Board will provide strong leadership to KHNZ in 2019/20.

Third, and most significantly, there have been substantial changes in the staffing of KHNZ over the past year. Jacqui Jeffrey joined KHNZ in late 2018 as fundraising co-ordinator. Max Reid resigned as Chief Executive in December 2018, and Carmel Gregan-Ford agreed to step in as acting Chief Executive between December 2018 to July 2019, while the search for a successor took place. Michael Campbell joined KHNZ as General Manager in July 2019. Carmel Gregan-Ford left KHNZ in July 2019, although she has been supporting KHNZ on a contract basis for key events since July. Chrissy Taylor and Sandy Speedy have been providing on-going support for patient and family enquiries through the 0800 number, on operations in the 2018/19 financial year, but this was more than offset by an increase of $319,748 in the value of KHNZ’s investment portfolio.

Overall, KHNZ is in a solid financial position in the short term, but we need to develop sustainable sources of income to maintain and grow KHNZ in the medium term.

In terms of the substantive work that KHNZ does to support kidney patients and their families, two things stand out from 2018/19.

We have continued to provide a high level of support, through over 600 enquiries to the 0800 number, 12 education sessions provided to patient/family and health professionals, and a range of engagements with local patient groups and Members of Parliament. In addition, the progress made in 2017/18 on the Deceased Organ Donation Strategy, launched by the Government in June 2017, was followed up by the introduction into Parliament the Organ Donors and Related Matters Bill in early 2019. This legislation will give the New Zealand Blood Service a leadership role in the promotion of organ donation (including Kidneys) across New Zealand – one of the key planks of the Deceased Organ Donation Strategy. While we welcome the intent of the legislation, our submission to the Health Select Committee argued that the Bill could be made stronger by being clearer about the objectives, functions and accountabilities of the Blood Service. We also argued that the whole of the Deceased Organ Donation Strategy should be fully funded, including adequate funding for the Blood Service’s new responsibilities. While the Select Committee’s response to our submissions was disappointing, we will continue to work across the political spectrum in Parliament to ensure that the Strategy is fully implemented.

Fourth, last year I reported that in early 2017 the Board agreed to terminate its telemarketing fundraising contract amongst concerns about how the fundraising was being handled. A new contract for KHNZ, intended to diversify the fundraising base of the organisation, will take some time to fully develop and implement. As a result, KHNZ made a loss ($197,786) in the financial year, but this was more than offset by an increase of $319,748 in the value of KHNZ’s investment portfolio.
General Manager’s Report

Kia ora

The year has been a year of challenge, farewells and new beginnings. Jacqui Jeffrey joined the team at the start of the financial year as fundraising coordinator following on from a review of Kidney Health New Zealand’s fundraising strategy. Jacqui is an experienced fundraiser and continues to grow the organisation’s funding sources. Kidney Health New Zealand farwelled CEO, Max Reid in December 2018 as he headed off to new opportunities in Dunedin. For the rest of the year, Carmel Gregan-Ford took on the role of acting CEO while a new strategy was developed, and GM was appointed.

The organisation also farwelled long-serving National Education Manager, Carmel Gregan-Ford in August 2019 after seventeen years with the organisation. Carmel is still working in the renal area and continues to undertake contract work for Kidney Health New Zealand. Carmel’s contribution to kidney health throughout New Zealand is second-to-none. Here seventeen years is recognised in the mantra of the organisation as she has been the face of kidney health in New Zealand and more recently also the leader of the organisation. Many of the innovations and developments within the renal space are due to her efforts over the years. Kidney Health New Zealand wishes her well in her new endeavours and hopes to continue its relationship with Carmel in a different capacity.

The organisation undertook a significant review to develop a new strategy for the organisation during 2018 and 2019 including engagement with the Consumer Council and support groups. The new strategy is commencing its implementation phase and is available to view on Kidney Health New Zealand website and in this annual report. As part of the strategy, Kidney Health New Zealand undertook to engage and support regional patient support groups and will continue to do so. During the year a number of activities were undertaken particularly around World Kidney Day.

Kidney Health New Zealand continued to invest in research with work by Professor Suetonia Palmer and Dr Rachael Walker being presented to the Consumer Council. Professor Palmer, Dr Walker along with Dr Michael Collins are also working with Kidney Health New Zealand to look at ANZData (the data collected regarding all renal patients) and other research to be undertaken, to identify how it can be refined to better meet the needs of kidney patients. This includes CKD, dialysis, transplant and other kidney issues.

“Away from home” dialysis continues to be deemed as a significant issue for renal patients. Kidney Health New Zealand is working with the National Renal Advisory Board to develop a strategy to be passed to District Health Boards to help support dialysis patients to move freely within New Zealand. Inequities also continue to be a significant issue for renal patients with identified gaps based on ethnicity, gender, regional and rural delivery of health outcomes. Kidney Health New Zealand continues to develop plans to lobby, and where appropriate lead, strategies to eliminate these inequities.

As the new GM I am very grateful for the amazing welcome from the renal community and I am working hard to meet with everyone within the renal community. The success of Kidney Health New Zealand is due in no small measure to a small very dedicated team, Max and Carmel over four and seventeen years respectively, Deanne Hock, the diligent office administrator of thirteen years, recently joined Jacqui Jeffrey and medical adviser Dr John Collins.

Financial sustainability continues to underpin Kidney Health New Zealand’s strategy. The organisation is grateful to all its generous donors and hopes that this generosity can continue to grow based on the value of the work Kidney Health New Zealand undertakes. With new staff and board members Kidney Health is positioning to continue to grow, based on the work of its long serving staff and board members and on the new team.

Michael Campbell
General Manager

Medical Advisor’s Report

I was appointed to the KHNZ Medical Advisor role in 2019, having been in an acting role for the latter half of 2018. As the title suggests this part-time role is to provide a professional nephrology perspective on medical issues. During the past year I have worked closely with the outgoing national education manager, Carmel Gregan-Ford who has made an outstanding contribution to kidney education and care in New Zealand.

Much of this work has been in relation to Chronic Kidney Disease (CKD) which is an important focus for KHNZ. The key principles in patient care are: early detection, appropriate medical management in Primary Care and timely referral to Renal Services. KHNZ undertakes screening at public events and on World Kidney Day. The recent acquisition of a point of care device for measuring serum creatinine will enhance the breadth of screening. However, we recognize that most screening occurs in Primary Health Care and so KHNZ provides a number of educational tools and talks for primary health professionals along with its informative website. Closer collaboration with Primary Care will be important to ensure optimal screening and patient care is occurring along with continued advocacy at a Ministry of Health level.

New medication developments from international research are worth noting: SGLT2 inhibitors, have been shown to improve blood sugar and blood pressure management leading to heart protection and improved survival in people with Type 2 Diabetes. A large study published recently (2019) in the New England Journal of Medicine showed that one of these agents, Dapagliflozin, also delays progression of CKD in people with Type 2 Diabetes. It provided an additional effect to that of ACE inhibitors (such as lisapril, lisinopril and quinapril) which are the standard initial treatment for lowering Blood Pressure in diabetic kidney disease. Currently these are not funded and this needs to change given the large number of people in NZ with progressive kidney disease due to diabetes.

The number of people commencing treatment for End Stage Kidney Failure in New Zealand is now increasing at the rate of population growth, after exponential increases in the 1980s and 1990s (due to relatively rapid expansion of renal services across NZ and broader acceptance of most people with kidney failure in those decades). Some people with kidney failure decide not to have dialysis treatment. Most NZ Renal Centres now have a Supportive Care programme to provide ongoing care for these people in collaboration with their family practitioners, hospice and community support.

There has been a marked increase in deceased donor kidney transplantation rates in the 5 years to the end of 2017 with a small decline in 2018. Donation rates are approaching parity with Australia. However, despite this, there are many hundreds of people on dialysis waiting for a kidney to become available. KHNZ has continued its strong advocacy to promote transplantation throughout the community and at a governmental level. Legislation introduced to Parliament for the transfer of Organ Donation NZ to the NZ Blood Service, when passed into law, will further increase the number of deceased donors provided sufficient funds are allocated to enable full implementation. This needs to include better resourcing of ICU’s for donor assessment and management, and more extensive community promotion.

Blood Group incompatible kidney transplantation numbers are increasing sharply. However, there has been limited growth in transplants from the national Kidney Exchange program. This programme links patients whose donor is incompatible with other donor/recipient pairs in a similar situation. When the donor of one pair is compatible with another recipient and that recipient’s donor is also compatible with a different recipient, transplantation can occur. NZ and Australia have recently agreed to include both countries in a shared programme which will ensure much more opportunity for identifying compatible donor/recipient pairs and should lead to a significant increase in these transplants.

The Australia and NZ Society of Nephrology (ANZSN) is the professional body for all NZ and Australian nephrologists (renal physicians), kidney researchers and other renal professionals. It is reviewing its constitution and there is a proposal to open membership to patients and carers. They also plan to establish a more formalised relationship with both Kidney Health Australia and Kidney Health NZ in the areas of education, research, clinical quality and advocacy. This is good news for KHNZ and people with kidney disease living in NZ.

John Collins
Medical Advisor
National Education Manager’s Report

It has been another busy year for Kidney Health New Zealand with a number of educational and promotional opportunities taking place throughout the country. The following report highlights some of the activities.

Education and Awareness
I attended the Transplant Coordinators meeting where I gave an update on KHNZ as well as attending the education sessions. An article written for Canterbury Today publication promoting the work of KHNZ and the importance of good kidney health. I was guest speaker at a women’s interest group of 60 about our role and kidney health. Throughout the year I have given three lectures to the post graduate nursing programme for Otago University.

A Moari health Hu was held at Little River, this was a local initiative by the Community and Public health team, offering kidney health screening and advice, following on from this initiative I provided free kidney health checks and information at the inaugural Lyttleton Health Hub, this new initiative was supported by the local GP who donated her Medical Centre facility on the first Saturday of every month for health groups to offer free services to the community. This is a strength based collective, using a collaborative approach in promoting Community Action in partnership with Primary Care.

I was invited to join the Rural Health professional development programme – a Mobile Health initiative to provide access to health education via telehealth to General Practice staff in Whakatane, with more booked.

Education sessions were given to Year 10 students on Nutrition, Diabetes and kidney disease, as part of the health and nutrition curriculum.

I spent three days on the West Coast of the South Island providing education on Chronic Kidney Disease (CKD) to Primary care nurses from Westport, Greymouth, Hokitika, and Fox Glacier for Poutini Wairoa. Information sessions for patients and their families were held in Westport and Greymouth, with patients being transported from Hokitika to attend. Following these sessions, I carried out Kidney Health checks for many keen to know more about managing their health.

This year Napier Port Harbour to Hills partnered up with Kidney New Zealand as the preferred charity the Medical Advisor, Dr Colin Hutchison and I offered free kidney health checks at the event which was very successful and helped raise our profile in the area.

We have now added Te Reo translated audio visual resources increasing our suite of translated education resources.

World Kidney Day was Thursday 8th March, several renal units and patient support groups held events around this day.

Consumer Council
The Consumer Council meeting was held in March, Rachael Walker and Suetonia Palmer came and talked about the work they are doing around Patient Priorities in research. It has become clear in recent years that the priorities of researchers and clinicians are not always consistent with the priorities of patients and their families. It is also now widely recognised that patients and caregivers have vast expertise, knowledge and skills, and that harnessing these appropriately can lead to better clinical outcomes. This was a well-received session with them offering to report back at the next meeting on progress in this area.

Supporters survey completed and sent out via email and newsletter, the response was very positive with some excellent feedback and suggestions for areas to work on.

Chronic Kidney Disease
Following the Primary Care mailout, we received several requests for our resources from General Practices, the GP screening management guide and chronic kidney disease brochure being the most popular. I met with dieticians from NZ renal dieticians’ network to develop more targeted information for CKD patients, this is still in progress.

Continuing to work on a partnership with Polycystic Kidney Disease Australia. I continue to be involved with the ANZSN Dialysis Advisory Committee trying to ensure the NZ voice is heard, work continues clarifying the reciprocal agreement for dialysis treatment between Australia and New Zealand and developing Key Performance indicators for use nationally. The Key Performance Indicators (KPI) Working Group is currently reviewing international KPIs and related governance models and identifying a short list of KPIs for the Australian and New Zealand context. A formal governance process will be developed to support the implementation of the KPIs once approved. The Committee noted that obtaining consumer input on the KPIs will be important.

Conferences
I attended the annual Renal Society of Australasia (RSA) conference in Adelaide where I chaired a plenary session, adjudicated two sessions and presented our poster promoting the 0800 line, and made the closing address to promote the conference in 2019.

One of the highlights of the conference was Dr Gill Hicks an advocate for sustainable peace and a valuable resource in countering violent extremism. Gill is widely considered one of the world’s most thoughtful, powerful and life-affirming speakers.

Her devotion to making a personal greater contribution and positive difference to the urgency of building peace was realised when she was made permanently injured losing both of her legs in the London bombings on July 7th, 2005.

Her ‘lived experience’ -- from survival to rehabilitation as a double amputee -- created a clear demarcation from all she had known before the bombings. Her ‘second life’ is built on what she describes as a series of conscious choices, mindfulness and being aware of the importance of the moment. Gill shared what she has learned about herself, humanity and the extraordinary and inherent ability to rise in the wake of adversity.

I was on the organizing committee for the NZ RSA symposium held in Dunedin in October, the following day I helped run a patient kidney information forum for the local support group with about 30 patients, caregivers from the Otago Kidney Society and the Southland Kidney Society and staff attending, a variety of speakers provided some great education. Professor Rachael Walker used the opportunity to undertake a research pilot looking at Patient priorities for kidney care in New Zealand, with the group.

I was asked to be the convenor for the 2019 Renal Society of Australasian New Zealand conference, NZ gets to host this event every ten years, with over 450 delegates it will be a great opportunity.

I attended the annual GP conference in Auckland in July, where we had a stand with many of our resources on display. With 800 delegates it was the perfect forum to raise KHNZ profile and promote our resources. The feedback was very positive regarding our Chronic Kidney Disease screening guide for General Practice, many GPs use this when managing kidney patients. Definitely an excellent event to raise our profile and get the CKD message out there. It was exciting to know the GPs were not aware of the helpline but very keen to refer to it as needed.

The annual ANZSN Nephrology meeting in Queenstown, was another good opportunity to network and listen to some updates in nephrology. Together with our Medical Advisor Dr John Collins we wrote a submission to Ministry of Health requesting the inclusion of CKD questions in the National Health survey. The response from the Ministry was encouraging and as follows “The 2014/15 NZ Health Survey included questions on CKD (doctor diagnosis and treatments). These results haven’t been published yet.”

There has been an increase in email requests for support and information, more common requests include, considering being a live kidney donor, holiday dialysis, newly diagnosed with kidney disease and wanting to know what this means and many others. The 0800 line has also received over 600 calls and continues to be well utilised.

Carmel Gregan-Ford
National Education Manager
OUR STRATEGIC GOALS (to 2024)

1. NATIONAL AWARENESS
   KHNZ extends its reach so we are positively impacting everyone affected by, or at risk of, kidney disease
   1. Utilise multiple local and national communication channels to position KHNZ as the national voice on kidney health matters
   2. Work with agencies and communities to reduce national inequities in access to kidney health support and dialysis for all New Zealanders (in particular: Maori, Pacifica, rural and remote communities)

2. INFORMATION & SUPPORT
   KHNZ is recognised nationally as the primary source of information on the prevention and management of kidney disease
   2.1. Actively source opportunities to support people affected by, or at risk of, kidney disease
   2.2. Deliver resources, information and education programmes through multiple local and national channels (online, face-to-face, paper, media...)
   2.3. Design a scalable education delivery and information sharing model

3. SUSTAINABILITY
   KHNZ is financially strong and structured for sustainable growth
   3.1. Grow revenue to fund the organisation and ensure sufficient reserves are maintained to cope with fluctuating income
   3.2. Ensure KHNZ is structurally fit-for-purpose
   3.3. Attract, retain and train the best people

4. ADVOCACY
   KHNZ is recognised as an influential voice and the national advocate for people affected by, or at risk of, kidney disease
   4.1. Develop a structured and deliberate engagement strategy to advance our mission
   4.2. Gather evidence to support and validate key issues facing people affected by, or at risk of, kidney disease
   4.3. Engage with the government, public and business decision-makers on issues and the practical actions to support people affected by, or at risk of, kidney disease

5. LEADING & COLLABORATING
   KHNZ collaborates with stakeholders on bilateral initiatives and provides national leadership to support local kidney groups and societies to achieve their objectives
   5.1. Codify the relationship between KHNZ and kidney groups/societies/organisations involved in promoting kidney health
   5.2. Collaborate with strategically aligned organisations to collectively improve health outcome for all New Zealanders

6. SERVICE DELIVERY
   KHNZ deliver, subject to funding, products and services that promote better kidney health and support those affected by, or at risk of, kidney disease to live full lives
   6.1. Co-ordinate away-from-home dialysis
   6.2. Deliver year-round programme of outreach to patient groups
   6.3. Standardise screening for all New Zealanders

OUR VISION
Better Kidney Health for all New Zealanders

OUR MISSION
The national voice for people affected by, or at risk of, kidney disease

GUIDING PRINCIPLES
KHNZ is committed to maximising the wellbeing of people affected by kidney disease by:
- Prevention and early detection of kidney disease in people at high risk of kidney disease
- Promotion of best practice in the management of people with kidney disease
- Maximising kidney transplantation

VALUES
- The pursuit of the highest standards of professionalism, quality and ethics
- Supporting the diversity and the independent roles of support organisations
- Collaboration through working with staff, volunteers, kidney support organisations, health professionals and the public
- Supporting the human rights and autonomy of patients with kidney disease and their families
summary financial statements
for the year ended 31 march 2019

a full set of audited accounts is available upon request from kidney health new zealand, PO box 20072, christchurch

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

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

remembrance donations
John Gallen
Geoff Murphy
Piri Waata Nathan
Nani Narasy
Thomas Whetu
Sik Wai Tsai
Brendon John O’Connor
Robert Brydon
Richard Lionel Lewis
Jenny Standen
Graeme Wilson
Gopalbhai Dullabh Mistry
Raymond Davis
Ian McLeod
Kevin Francis Haddock

bequests
Estate Winchester
Estate Tonya Kara

donations - $500 and over
Dipton War Memorial Hall $2,000.00
Averil Langrell $750.00
J B W McKenzie Trust $1,000.00
Helena Pedley – Birthday $1,320.00
Sepoima Lotam $17,000.00
Nicole Manilal $1,074.50
Heather Doudle $1,200.00
Seth Coleman $4,700.00
Sean Hogan $1,285.69
Helen Kettles $2,537.00
Lotteries $17,250.00
Pub Charities $10,000.00
The Lion Foundation $10,606.00
Steadfast Foundation $7,500.00

summary financial statements
for the year ended 31 march 2019

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

summary statement of financial performance

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<th>2018/19 This Year</th>
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summary statement of financial position

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