Sioney Health NEW ZEALAND



Prevention • Support • Research



Chairman's Report

BOARD OF TRUSTEES

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Michael Papesch (Wellington)

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Assoc. Prof. Richard Robson (Christchurch) (resigned Feb 2020) Nick Polaschek (Wellington) John Kearns (Auckland) David Shearer (Christchurch) Traci Stanbury (Christchurch) Natalie Brown (Dunedin) Christine Prince (Christchurch) (joined November 2019)

KIDNEY HEALTH NZ STAFF

General Manager

Michael Campbell (joined July 2019)

Medical Director

Dr John Collins

National Education Manager

Erica Fairbank (Auckland) (joined November 2019)

Administrator

Deanne Hock (Christchurch)

Fundraisers

Jacqui Jeffrey (Christchurch) Anne Hindson (Christchurch)

CONTACT DETAILS

Kidney Health New Zealand Unit 7/337 Harewood Road Christchurch

Phone 0800 KIDNEYS (543 639) Email info@kidney.health.nz Website: www.kidney.health.nz Find us on Facebook: Kidney Health New Zealand Kidney Health New Zealand is now over 40 years old.

In November 2019, His Excellency, Sir David Gascoigne hosted a reception celebrating the 40th anniversary of KHNZ at Government House. Over those many years, individuals, groups and benefactors have supported us faithfully to ensure Better Kidney Health for All New Zealanders. My heartfelt thanks to everyone who has been part of this journey. However, as much as we can all be proud of some fantastic achievements, there is still more to do.

As well as the business as usual aspects delivering services throughout New Zealand, this past year has seen KHNZ undertake some significant transitional changes to build a stronger future focused organisation and array of services to support patients and frontline kidney services throughout New Zealand. One new service was the KHNZ National Roadshow programme. This project, generously supported by a number of national and regional supporters, sought to:

- Assist in prevention and early detection of kidney disease in people at high risk of kidney disease
- Identify regional support exemplars and information gaps
- Promote best practice in the management of people with kidney disease
- Connect with the tireless volunteers in kidney societies, renal community and DHB's who are the face of patient support for those of us with kidney disease.

Despite the success of the roadshows, the past year has been one of the toughest. Coupled with COVID-19, the departure of long-term employees, new team members, uncertainty around fundraising and policy changes have all contributed to a very difficult operating year. While always disappointing to make a small loss, it needs to be contextualised within this operating environment. Our vulnerability to discretionary income streams remains acute and is a crucial area of focus for the Board and operations team.

In 2021, our strategic challenge is to update our educational material, deliver a comprehensive range of patient support programmes and roadshows in a financially constrained operating environment. Consequently, the Board have committed to underwrite the continued delivery of:

- national service programmes,
- research into equitable access to nephrology care for rural patients.

Notwithstanding our progress to date, we still have the opportunity to improve the levels and types of support for those experiencing, or at risk of kidney disease. There is still the challenge of raising awareness as we know that one in ten will be affected directly and many more through family. We also need increased facilities for home dialysis, to encourage kidney donation and transplantation, and to fund research – which were the original purposes of the National Kidney Foundation in 1979. Add to that the inequities in health delivery and we still have much work to do.

We know we can't address these opportunities and challenges alone and are working hard to collaborate with like-minded parties to develop sustainable services. These include working with:

- MOH and PHO's and at-risk 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),
- New Zealand Blood Service to deliver the deceased organ donation strategy,
- Renal specialists (NRAB ANZSN), consumer groups (regional patient societies, KHNZ Consumer Council), and sister organisations like Kidney Kids.

As the incoming Chair of KHNZ, I want to thank my fellow directors Michael Papesch, John Kearns, Traci Stanbury, Nick Polasheck, Natalie Brown and Christine Prince. Their advice and support have been invaluable. Much of the period covered by this annual report was overseen by the outgoing Chair Michael Papesch and we acknowledge his substantial contribution to the governance of KHNZ in the eight years that he was a member of this Board.

On behalf of the Board I extend our sincere thanks to GM Michael Campbell and his team for their outstanding performance during a challenging year. The speed and assured manner with which the team updated information, established FAQ and advocated for dialysis access meant the renal community was extremely well served during the COVID-19 lockdowns. Finally, the Board also pays tribute to Trevor Roberts, KHNZ Board member who died in October. Trevor was a tireless advocate for KHNZ and we will remember his generosity and service.

We look forward with great confidence to the future but rest assured, we are also working extremely hard as an organisation to do ourselves out of a job. But we are not there yet. As such my thanks to all of you, and our partners, supporters and colleagues for continuing to support KHNZ to achieve Better Kidney Health For All New Zealanders.

David Shearer Chair, Kidney Health New Zealand

Michael Papesch

KHNZ would like to acknowledge the valuable service of outgoing Chair Michael Papesch. Michael served on the Board for eight years from 2012 until 2020 and was an astute and effective Chair and governor. During his three years as Chair he oversaw significant structural changes within the organisation and sector, consolidated our advocacy and policy strategy and pushed for nationally equitable renal services. Michael also played a key role advocating for fully funded centralised organ donation via New Zealand Blood Service. While we wish Michael well in his future endeavours, we will miss his intellect and humour but we are confident we will see him again.



General Manager's Report

2019 was an initiation year for me, joining KHNZ in June and then having to immediately recruit new staff, work with Jacqui and Deanne to organize our very successful 40th anniversary event, meet with Associate Minister of Health, Peeni Henare, work with the team to design a new engagement programme (our Roadshows), organize World Kidney Day, cancel then run online our Consumer Council.

We farewelled Carmel Gregan-Ford at the end of July 2019. Carmel had successfully led Kidney Health New Zealand as National Education Manager for 17 years including being acting CEO from December 2018 to June 2019 and through the Christchurch earthquakes where KHNZ operated from Carmel's sleepout.

We then began a recruitment process appointing Erica Fairbank as National Education Manager. Erica is based in Auckland and travels throughout the country to meet with DHBs, PHOs, GP practices, support groups, patients and undertakes screening of those at risk of CKD. She also responds to enquiries from our free 0800 (Kidney) line, emails (info@kidney.health.nz) and our Facebook page (https://www.facebook.com/kidneyhealthnz).

The board set out an exciting strategic plan available overleaf. We set about developing an operational plan to achieve these goals. Obviously other events have gotten in the way however we are excited with the plan we have developed. The plan has KHNZ travelling to all regions of New Zealand. The plan was approved at the February 2020 board meeting and we have started to implement the plan and will report on this at next year's annual report, in upcoming newsletters. You can also follow our progress through our Facebook feed.

We also worked with the National Renal Advisory Board to identify how KHNZ can better engage with the NRAB and DHB renal units and met regularly with the New Zealand Blood Service to engage regarding the implementation of the Organ Donation Strategy.

We met with Associate Minister, Honourable Peeni Henare to lobby for more funding for the New Zealand Blood Service to assist in the development of the "Increasing Deceased Organ Donation and Transplantation: A National Strategy" which has been enabled by the passing of the Organ Donors and Related Matters Act 2019. KHNZ has been closely involved in lobbying for the strategy and the passing of the act, meeting MPs and Ministers and presenting to the Health Select Committee. There are more details on the strategy here: https://tinyurl.com/yyh3nfa3. We would encourage you to read the material and to speak to your MP to make them aware of the need for funding for the proper implementation of the strategy as to date the Act only enables the moving of Organ Donation NZ from ADHB to the Blood Service. KHNZ believes that funding of the strategy will ensure its success.

We had an excellent event hosted by His Excellency, Sir David Gascoigne to celebrate 40 years of KHNZ at Government House in November. We also ran the AGM on the same day at the Customhouse. Photos are available here: https://www.kidney.health.nz/News-Events/

We organized the Consumer Council for March 2020 with invitations accepted, flights, meeting room and refreshments booked and then had to cancel all the arrangements due to the Covid lockdown. However, we had a very successful online Consumer Council meeting and we thank all the participants.

Our support groups have continued to work closely with KHNZ and during the lockdown we ran five online meetings with all support groups. We are grateful for their continuing support of the kidney community in their regions. Financially, all charities are being challenged by the current situation and need all the support KHNZ can get. You can see the support KHNZ has received through 2019 in this report and the board and team are extremely grateful for the support of donors, no matter the size of the donation.

See details here of how you can help: https://www.kidney.health.nz/Support-Us/

I would like to thank Deanne, Jacqui, Erica and Anne along with the board and the kidney community for the camaraderie, support and collaboration as KHNZ has navigated such uncertain times and at the same time commenced some very exciting initiatives to improve our services of prevention, support and research.



Medical Advisor's Report

2020 has been a difficult year for all of us with the COVID19 pandemic. People with kidney disease and particularly those on dialysis were shown overseas to be at higher risk of serious illness and death from this viral infection. New Zealand dialysis units implemented very tight access and management protocols for all patients undergoing regular centre dialysis, which have been effective in preventing COVID infections in this vulnerable group. However, the lockdowns resulted in delays for medical reviews and surgery for many people, increased mental stress and isolation and reduced transplant activity. Many doctors undertook consultations by phone or online which suited some people having routine follow-ups but was unsuitable for people with more complex issues or those requiring physical examination where in-person consultation is essential. It has been suggested that it will take 18 months for DHBs to catch up with the backlog in surgeries. This is not so much a lack of financial resource but a lack of capacity of both personnel and facilities. Efforts to prioritise the most vulnerable, particularly Maori and Pacific people are important. Rates of kidney transplantation had been increasing up to the lockdown and are likely to rise significantly in the latter part of 2020. In 2019 there were 45 new transplants/million population, the highest number ever. Detailed information on dialysis and transplantation activity in Aotearoa New Zealand can be found on www.anzdata.org.au.

New treatments are being introduced for those with diabetes. Type 2 diabetes affects more than 250,000 people in NZ. Maori and Pacific people are three times more likely to suffer from diabetes and twelve to fifteen times more likely to develop kidney failure from diabetes. Uncontrolled diabetes also causes eye disease, nerve, heart and vascular disease. Two new diabetes treatments, Empaglifozin (Jardience) and Dulaglutide act in different ways to reduce blood sugar but also achieve the additional benefits of reducing damage to the heart and kidneys. Pharmac has recently completed consultation on the use of these treatments and it is expected that Jardience will be funded for use in December this year with the other treatment becoming available after registration is completed, probably late this year or early next year. Pharmac proposed that they be restricted to people with diabetes who already have kidney disease (even very early disease) or have heart disease or a high risk of developing it, although these criteria may change following the recent consultation. It is nevertheless very important for people with diabetes to be screened at least yearly by their family doctors for any evidence of kidney disease. Along with recommended life-style management, standard medications to lower blood sugar (e.g.metformin and insulin), and blood pressure medication, people with early kidney disease such as increased urine albumin or reduction in GFR (eGFR<60 mls/min) may soon be eligible to receive treatments to reduce the risk of further kidney damage and protect against heart problems.

Chronic kidney disease (CKD) can be a devastating condition and regardless of the underlying cause, it is slowly progressive and leads to irreversible nephron loss, severe kidney disease, dialysis or transplantation and/or premature death. Factors that contribute to CKD progression include kidney cell loss, chronic inflammation, fibrosis and reduced regenerative capacity of the kidney. Current therapies are effective in delaying disease progression but do not cure CKD. There is a need to develop new treatments to either stop or reverse progression. Preclinical studies have identified several approaches that reduce fibrosis in experimental models and some of these kidney protective strategies are now being tested in clinical trials.

However, many people with kidney disease and some with diabetes are unaware that they have these serious health issues. Maori and Pacific people who have worse outcomes are less likely to access screening and treatment programmes. The reasons include socioeconomic issues and a healthcare system which is not well aligned to Maori and Pacific world views. Unlike screening for cervical or breast cancer, there are no national screening programmes for kidney disease. KHNZ has strategic goals to standardise kidney screening for all people and work to reduce inequities for access to kidney therapies for Maori and Pacific peoples. KHNZ provides some free screening and also encourages people with a high risk for kidney disease to get themselves screened by their family doctor. In summary there is progress in the diagnosis and management of kidney disease but much more needs to be done in the areas of research and healthcare provision, and also at an individual level ensuring screening and optimal treatment occurs.

John Collins Medical Advisor



National Education Manager's Report

Kia Ora all.

I was appointed as the new National Education Manager at the end of November 2019. It has been an interesting year and I have had many opportunities for teaching and promoting Kidney Health.

Home Haemodialysis meeting

On the brink of starting the new role I attended the annual meeting of the home hemodialysis teams. This was a very informative and helpful get together and I learned of the many differences between regions. The teams were from Waikato, Northland and all Auckland DHBs.

Education and awareness

I undertook education sessions for nursing students from Otago University. I was invited to the annual renal dietitian meeting and presented the dietary enquiries we receive through the 0800 helpline, emails and Facebook. This was very helpful for both KHNZ and the dieticians and I am excited to increase our collaboration with Dietitians NZ.

I was asked to undertake screening for 70 + staff members in a large company. I did different shifts to capture as many staff members as possible. The stat sensor funded by Steadfast Foundation is a very helpful tool and used when its evident someone is at risk of Kidney Disease. The staff were very grateful, and some had also brought family members. Some staff and family members were found to be at risk, and they could be followed up by their GP. We are keen to work with companies that would like us to undertake screening for their staff and community.

I was invited as guest speaker at the Kidney Health Forum in Invercargill run by the Southland Support Group. There were donor and recipient guest speakers as well as some people who are on Peritoneal dialysis and stories shared by a former dialysis nurse. This was a great forum and well received.

Early in the year I met with the private hypertension specialist in Auckland City and attended one hypertension clinic at WDHB. They work closely together. I presented Kidney Health NZ at one of the quarterly meetings of the hypertension group. I have since joined the group.

World Kidney Day was on Thursday the 12th of March this year. I had contacted all DHBs and support groups to encourage them to get involved with World Kidney Day. Everyone joined in which was very positive. KHNZ supplied t-shirts, posters, pamphlets etc. We even had companies ring up that wanted to have posters in their staff room to celebrate World Kidney Day. I was able to help out at 2 locations and hired another stat meter so we could screen more people. ADHB wrote a great report about their day and you can find this on our website: https://tinyurl.com/y4xkm7e5

What was very nice this year is that we were able to connect Southland Institute of Technology nursing department and the Southland support group together and they helped out together on World Kidney Day. Both groups really enjoyed the collaboration. We are keen to model this throughout the country.

We were able to have a stand on the steps of parliament two days before World Kidney Day. We managed to get some of the politicians checked and the NZ Herald and TVNZ took photos of Trevor Mallard and Simon Bridges getting a Kidney Health check which is great for raising awareness.

Unfortunately, after World Kidney Day the world as we know it changed. The Pacifica festival which we were intending to attend was cancelled at the very last minute and we all went into lockdown the following week. My focus in lockdown was to support patients, DHBs and GP Practices. We worked closely with DHBs to ensure we got the right information to patients and take some of the pressure off frontline health professionals.

During lockdown we also received funding from MSD for some automatic blood pressure monitors and I was able to distribute these to patients whose DHBs were keen to see stay at home and report their blood pressure to their GP rather than risk venturing out.

CKD workgroup

I have joined the RSA Chronic Kidney Disease workgroup. This is a helpful group and we learn from each other. There are Australian and New Zealand members. This is organized through the RSA. Once every two months we meet and discuss education material, patient care etc.

Resources

There has been a steady request from the 0800 helpline and emails for support and information. This also helps me to map out were there are gaps in the system. Thanks to Carmel, Kidney Health NZ has a lot of helpful resources, this is utilized well by patients and staff. I have added a Tuvaluan translated video and some Tuvaluan translated pamphlets. I also added information about Polycystic Kidney Disease with support from John Collins. GP practices continue to request the CKD management guidelines. This, together with KHNZ videos seem to be our most popular resources.

Donor support group: Kidney Donor Whanau

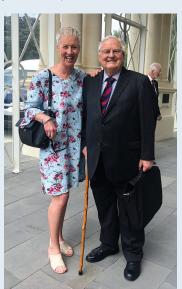
In February I met with Leah Stewart. Leah had donated a kidney to a friend a few years back. She asked if there was a donor support group. KHNZ agreed to support her in setting one up as I also have received questions from donors on the 0800 helpline and the new support group find it a nice way for donors to connect and support each other. Kidney Health NZ supports the group when any medical questions arise. The response to this group has been very positive from donors as well the transplant teams and I am enjoying working closely with Leah.

Erica Fairbank
National Education Manager

Obituary - Trevor Athol Roberts

It is with deep sadness that Kidney Health New Zealand report the passing of Trevor Roberts at Wellington Hospital on 6 October 2020. KHNZ passes it sympathies to the Roberts family. Trevor was a Wellington lawyer with personal or professional association with people with kidney disease. Trevor was one of the key figures in the early days of the National Kidney Foundation of New Zealand. When the Foundation moved its headquarters from Palmerston North to Wellington in the early 1980s, he worked closely with Dr Bruce Morrison, head of the kidney unit at Wellington Hospital. They were a formidable team in gaining the ear of policymakers and potential donors. His time

on the Wellington District Health Board and in later life as a patient gave him a deep insight into how hospitals Throughout run. Trevor's long association with the Foundation (and later Kidney Health New Zealand) he provided legal advice pro bono and wrote the constitution when the Foundation became Kidney Health New Zealand. Trevor was awarded honorary life membership of Kidney Health New Zealand due to his substantive involvement with the organisation. At the time of his passing he was compiling a history of Kidney Health New Zealand. He will be sorely missed by the Kidney Community.



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

- 1.1. Utilise multiple local and national communication channels to position KHNZ as the national voice on kidney health matters
- 1.2. 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
- 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 2020

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

SUMMARY STATEMENT OF FINANCIAL PERFORMANCE	2019/2020	2018/2019
	This Year	Last Year
Revenue		
Donations, fundraising and other simliar revenue	\$296,468	\$83,610
Revenue from providing goods or services	\$10,722	\$42,410
Interest, dividends & other investment revenue	\$118,222	\$101,615
Total Revenue	\$425,412	\$227,635
Expenses		
Expenses related to public fundraising	\$2,396	-
Volunteer and employee related costs	\$236,253	\$238,637
Costs related to providing goods or services	\$158,864	\$158,068
Grants and donations made	\$6,724	\$2,700
Other expenses	\$29,484	\$26,016
Total Expenses*	\$433,721	\$425,421
Surplus/ (Deficit) for the Year	-\$8,309	-\$197,786
Other comprehensive revenue and expense		
Fair value movement in available for sale instruments	-\$56,790	\$319,748
TOTAL COMPREHENSIVE REVENUE & EXPENSE FOR THE YEAR	-\$65,099	\$121,962
SUMMARY STATEMENT OF FINANCIAL POSITION		
Current Assets	\$106,784	\$88,652
Fixed Assets	\$7,096	\$7,385
Investments	\$3,235,636	\$3,311,500
Total Assets	\$3,349,516	\$3,407,537
Current Liabilities	\$29,426	\$22,348
Total Equity	\$3,320,090	\$3,385,189

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

Melissa Jane Symes Marilyn Kaye Beeston Jim Wilde David William Murphy Carl Schrama Anita Milicich Dorothy Reddish Linda Clark Muriel Gibb Catherine Chaston Margaret Sloane Melanie Hall Eddie Yeow Dahyabhai Kanji Alan David Morrison Glynis June Gibson Debbie Tims

BEQUESTS

Estate Agnes Ada Price Estate Vernon Roach Scull

DONATIONS - \$500 AND OVER

The Trusts Community Foundation \$5,000.00
One Foundation \$5,722.27
Averil Langrell \$750.00
Mrs P Mabbett \$600.00

res, I want to neip 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.

