

Prevention • Support • Research

It is hard to believe that Christmas is just around the corner already; it seems the older I get the faster the years seem to fly by and this year is no exception!

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Hawkes Bay Health Forum

In September Kidney Health New Zealand were invited by the Hawkes Bay District Health Board to participate in the Hawkes Bay Health Forum – “Love your Kidneys”. It was a full on two days with Kelvin and I talking to a variety of groups about kidney disease, it’s impact and what can be done to try and decrease the numbers with Chronic Kidney disease.

There was a large turnout for all 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 we spoke to around 300 people over the two days. The staff at Hawkes Bay DHB looked after us exceptionally well and due to its success we are now looking at holding a similar programme in other regions in 2015.

Below: Kelvin Lynn speaking to some of the Hawkes Bay Health professionals at one of six sessions held in total.



KHNZ's Manifesto

Our blueprint for better and lower costs services to renal patients in New Zealand includes:

1. Address the low rates of deceased renal transplantation.

New Zealand's rate of deceased renal transplantation is amongst the lowest in the Western world; being amongst the best would lead to about an extra 100 transplants in New Zealand a year.

We propose establishing a Ministerial enquiry to identify how the world's best practice can be applied to New Zealand.

2. Facilitating pre-emptive live transplants.

While health professionals accept the benefits of pre-emptive transplantation (that is, undertaking a transplant -if possible -before starting dialysis), there is variation in practice across the country with a range of <10 to 45 percent of all live donor transplants being carried out pre-emptively. We propose setting a KPI for the new National Renal Transplantation Service for pre-emptive transplantation at 45% - the NZ benchmark -and develop methods for providing a financial incentive for DHBs to increase pre-emptive transplantation.

3. Reimbursement of live donors' expenses.

New Zealand currently only reimburses donors for lost income to the level of the Sickness Benefit – up to \$335/week. This amount does not meet the national median mortgage costs of over \$400/week, let alone other living and medical expenses incurred post-discharge. We propose that a programme be developed to fully re-imburse the costs (including loss of income) for live kidney donors be developed by the Ministry of Health based on the Financial Assistance for Live Organ Donors Bill. The costs of this programme would be met from the under spent existing appropriation in the Ministry of Social Development.

4. Reducing barriers to home dialysis.

Currently there are about 2,500 people on dialysis in New Zealand. Dialysis can be performed independently by the patient in their home, or undertaken in a dependent fashion by staff at a facility. Fewer New Zealanders are choosing home dialysis even though improving the uptake of home dialysis will increase the longevity and quality of life of dialysis patients, and reduce costs. We propose that the Government set a national target of at least 65% of dialysis patients on a community-based therapy and task the Ministry of Health to actively support the National Renal Advisory Board to develop national practice standards for home dialysis.

5. Improve support for home dialysis patients.

Home dialysis patients take responsibility for their own dialysis and save about \$30,000 annually each by not using more expensive hospital based dialysis.

However patients and their carers report that they often feel unsupported and question why in some parts of the country out-of-pocket expenses, from \$500 to \$1,000 annually depending on the dialysis type, are not reimbursed by their DHB. We recommend that the Ministry of Health co-ordinate a stock take of DHB policies to reimburse home dialysis patients for out-of-pocket expenses, and develop policies to ensure that DHBs reimburse home dialysis patients.

6. Access to "Away from home" haemodialysis

Patients on dialysis cannot take a break from treatment. This presents challenges when patients require haemodialysis treatment when they travel away from their base unit or home (if on home dialysis) for business or as part of their work. In many cases, this may mean that a patient has to change their job or stop working: neither outcome is conducive to their full rehabilitation. Improved access to "away from home" dialysis would increase the opportunities for some dialysis patients to get a job. For all dialysis patients and their carers, difficulties in accessing holiday dialysis can lead to carer burnout and depression for haemodialysis patients. If patients and/or carers experience burnout they are likely to revert to more expensive and, for many who live distant from the renal unit, inconvenient, hospital dialysis. Holidays and other trips from home are an essential part of renal replacement therapy and the lack of this provision can have a detrimental effect on patient welfare and outcomes but there are issues with New Zealand renal units' capacity to accept out of town patients and a lack of national co-ordination. KHNZ recommends that the Ministry of Health, in consultation with the NRAB and KHNZ, develop proposals for the Minister's consideration on including provision of facilities for "away from home" dialysis (including holiday dialysis) as part of the standards of dialysis care.

7. Improve GP knowledge of management of CKD.

Most CKD is managed in primary care. Most people with CKD do not know they have the condition. Early detection and treatment reduces the important complications of CKD –heart disease, kidney failure and premature death –by about 50%. But there is no national education programme for GPs and practice nurses. There is evidence of patchy performance by primary care in recognition and management of CKD.

We recommend that the Ministry of Health develop a proposal for a national education programme on CKD management for primary care, including adopting and modifying the Kidney Check Australia Taskforce (KCAT) programme developed by Kidney Health Australia (KHA) for use in New Zealand.

If you would like to read the full document you can see it on our website at www.kidneys.co.nz or call me on 0800 543639 and I will send you a hard copy.

Walking New Zealand for Kidneys – an inspirational couple

Hugh Cole-Baker struggled with kidney disease for 10 years resulting in renal failure and the need for dialysis. In October 2013 Ros and Hugh Cole-Baker were admitted to Auckland Hospital for transplant surgeries that would take one of Ros' healthy kidneys and give it to Hugh. The transplant was a success and Hugh and Ros are grateful to have been on the receiving end of an enormous investment of skill and care. With Hugh's new lease on life the couple are passionate about doing something to help reduce the waiting list for others needing a kidney.

So, this spring they are facing another challenge. The Te Araroa Trail (www.teararoa.org.nz) leads walkers from Cape Reinga to Bluff, straight past Ros and Hugh's seaside bed and breakfast (www.tidesong.co.nz) near Whangarei Heads. Inspired by Te Araroa Trail walkers they have met, and motivated to cover some ground themselves,



Ros is setting out to complete the trail on foot and on mountain bike. Supported by Hugh in his "campervan of comfort", the couple will share the facts about live kidney donation and the benefits of a healthy lifestyle as they travel the length of New Zealand. On September the 18th they set off from Cape Reinga and they plan to be in Wellington by Christmas.

Ros and Hugh are available to talk about their journey to groups along the way. All enquiries welcome.

Ros and Hugh are supported by Kidney Society, Kidney Health New Zealand and Live Kidney Donation Aotearoa.

I have it on very good authority that following publicity about Hugh and Ros's journey in the local newspapers there have been at least eight people making enquiries about becoming live kidney donors in Northland – keep up the great work

Contact details:

Ros & Hugh Cole-Baker

Tidesong Bed & Breakfast

Mob: 022 0829244

F: www.facebook.com/walkingnzforkidneys

Some of us from KHNZ hope to join Ros and Hugh for a bit on the South Island leg.

Organ and tissue donation Awareness Day

New Zealanders got more than just a caffeine fix when they visited their local cafes on Saturday 11 October.

They were encouraged to have the all-important conversation with one another about organ and tissue donation as part of Organ and Tissue Donation Awareness Day.

The national awareness day was held on the same day as European Day for Organ Donation and Transplantation.

Transplant recipients all over the country visited their local cafes requesting their involvement. Stickers saying 'Have the conversation today' were placed on the top of takeaway coffee cups in participating cafes in the week leading up to, and including, Saturday 11 October. The stickers were intended to start a conversation within families about their wishes should they ever be in a situation where organ and tissue donation is possible.

Organ Donation New Zealand (ODNZ) also released a series of new brochures, posters and postcards on the awareness day. These feature images of six New Zealanders who have had the conversation with their family.

The purpose of the resources is to encourage the general public to learn more about organ donation and then have the conversation with their family.

"A great deal of thought and effort has gone into developing these new resources and we hope that they are well received and distributed. Death and dying are not something that people like to talk about but we hope the brochures dispel some myths that surround organ and tissue donation and encourage people to have that conversation with their loved ones," explained Dr Streat.

From www.donor.co.nz



Kidney Health New Zealand Educational Resources

Our biggest project recently has been the making of audio-visual information resource. I am very excited to announce it is now in the final stages of production, and looks amazing – not that I am the least bit biased, but I am confident it will be one of our most utilised resources when it becomes available. We are currently looking at a variety of options to make sure it can be accessed by as many people as possible.

The content includes;

- Understanding kidney disease
 - Looking after your kidneys
 - Treatment options
 - Peritoneal Dialysis
 - Haemodialysis
 - Supportive Care
 - Transplantation
- Including personal stories from patients

This resource will also be translated into other languages that are commonly used here in New Zealand; we are planning a special launch in Wellington in the near future, you can check out our Facebook page for future updates.

This is a purely New Zealand production, making it one of the first designed specifically for people living in New Zealand with kidney disease. We look forward to sharing it with you soon.

Kidneys in the News

Dialysis Patients Help Themselves to Treatment

Press Release: Waikato District Health Board

Shane Waraki and Jake Wharewhiti are in no doubt learning to do their own care at Waikato District Health Board's Regional Renal Centre in Hamilton has given them a quality of life they could only dream of months ago.

As part of the Assisted Care Programme, which was introduced in August 2013, they underwent a training programme, which then allows them to reach a target of at least 80 per cent independence with their haemodialysis treatment. This may include tasks such as setting the machines up, needling themselves and putting themselves on and off the dialysis machine.

Previously these patients would have been 100 per cent dependent on the nursing staff for all cares. They still require some nursing care for the other 20 per cent of the time. "I was eager to learn, it's in my nature. I do the needling myself now even though I was initially apprehensive," said Shane.

It gives him a sense of well-being and achievement. "I feel more in control of my own health. My family, especially my wife, think it is marvellous. She is my biggest supporter and she likes it."

Shane has been attending the Regional Renal Centre for nearly three years – the last 14 months for haemodialysis and 18 months before that on continuous ambulatory peritoneal dialysis.

Being able to help himself means he has more time with the grandchildren, can attend their school sports and help them out with their academic work. His eldest grandchild recently asked him what it was like so, after speaking to the dialysis staff, Shane brought two of his grandchildren to the centre to see for themselves.

"I'm teaching them now, saying to them that what happened to me, I don't want that to happen to them."

Jake is originally from Christchurch and transferred to Hamilton after the 2011 earthquake. He is about to head home having learned how to look after most of his dialysis cares through the Assisted Care Programme. "You can set your own goals as part of the programme, come in early and set it all up. I now have much more control about when my dialysis starts on allocated treatment days. "Jake has made life-long friends in the centre; it is a very social environment, he says. Plus he had his moment in the limelight at the centre's opening in November 2012 when he was part of a boy band which sang for Health Minister Tony Ryall. <https://www.youtube.com/watch?v=dKlxHsBQeCc>

Charge nurse manager Nicky Hagan said before the programme started all patients in the in-centre dialysis unit were fully dependent. Self-treatment means people can have a more independent, better quality life by fitting in the long treatments – up to six hours three times a week - into their routine, rather than having to attend set appointment times. It also frees up space in specialist units for people unable to manage at home or in the community. "We now have a group of patients who have some control and independence over their treatment.

"The ultimate aim of this programme is to see more patients go through to home training and eventually go home to be fully independent with their treatment, although this is not realistic for all patients in this programme," she said.

The Waikato renal service prides itself on the number of patients it has doing home based dialysis with around

65 per cent achieving this, which is above the national average. There are a number of patients unable to do dialysis at home for all kinds of reasons but can look after themselves with the security and support of the dialysis centre. “If we can get them doing a component of their own care to start with it might encourage them to go home. “It makes people more independent.”

The Regional Renal Centre has a capacity of 120 patients with the Assisted Care programme taking potentially 40 of those patients. Six of the dialysis stations in the \$7.6 million centre were not commissioned after opening and it is these being used at no extra cost.

Nicky saw an opportunity with using older machines from patients’ homes where newer machines had been put in. Waikato DHB has about 90 machines in people’s homes throughout the Midland region. The programme started with three patients but one of them was too ill and could not manage. The others trained over three weeks.

Research shows that patients who take on more responsibility for their own care have better health outcomes including quality of life. Nicky acknowledges some patients find doing their own home dialysis daunting but gain confidence by learning while in the centre. Some people have a needle phobia and may not be able to have treatment at home. “I am always still amazed at our patients who can line and prime the dialysis machine on their own.

Their families help particularly where there are disability issues.”

Missing the life-sustaining treatment is not an option. Nurse Suzanne English, who has been with the programme since the beginning and learned how to train patients from the home training dialysis nurses, says she has enjoyed it. “We see the same patients, they become our patients, and you go through everything with them. “They share everything with us,” she said. “A lot of these patients originally didn’t want to be independent,” says Nicky.

The centre sees 110 patients at the moment up from 85 when they opened nearly two years ago. When renal patients are in the in-centre unit, there is a 1:3 nursing ratio. Under the Assisted Care Programme it is a 1:5 nurse ratio. “This has allowed us to grow in patient numbers without increasing nursing staff. It also facilitates independence for patient care,” she says. They have trained 22 patients the past year.

Kidney failure is a growing problem in New Zealand with well over 2300 people now using dialysis. Around 80-100 new patients in the Midland region, which includes Waikato, Lakes, Bay of Plenty, Tairāwhiti district health boards, are expected to start dialysis in the next year.

The demand for dialysis services in New Zealand is predicted to grow at around 4-5 per cent each year over the next 10 years.

National Renal Transplantation Service

Dr Nick Cross has been appointed Clinical Director of the National Renal Transplantation Service and chaired the service’s first meeting on Wednesday (September 17, 2014).

It follows Health Minister Tony Ryall’s announcement last July that an extra \$4 million would be invested to increase the number of live kidney donor transplantations over the next few years.

Dr Cross says a lot of work has gone into developing this new service and it was great to have the Government’s financial backing.

“It’s been a carefully thought-out process with involvement from the Ministry of Health and other interested groups, DHBs and Clinicians. It’s really been a work in progress for probably the last two to three years,” he says.

Dr Cross is looking forward to the challenge of heading the service and says he could not have taken on the national role without the support of his colleagues.

“I’m very grateful to my colleagues around the country for their support and encouragement but particularly to the team here in Canterbury. Dr John Irvine has stepped into my former role in Canterbury as Clinical Director of Nephrology, which has allowed me to commit to this national role.”

The new service includes donor liaison coordinators who will work at each of the three transplanting centres and in the seven larger renal services in the country.

“These coordinators will support donors and recipients throughout the transplantation process, from providing education to interested potential donors to organising blood tests and carrying out pre-surgery preparation.”

There is also funding to provide increased support for the Paired Kidney Exchange initiative, which allows donor and recipient pairs who are not compatible with each other to be listed for a possible swap with other pairs.

Dr Nick Cross says Canterbury has relatively high live donor rates compared with the rest of the country, with an average of 10-15 per year, but some DHBs have considerably lower numbers in relation to their population.

“We know kidney transplantation significantly improves the quality of life and the long-term survival of patients with end stage renal disease. Fortunately Canterbury has worked hard to become a leader in live donor rates and hopefully through this development of a national service, we will see rates start to increase nationally.”

Dr Cross says he hopes the service will eventually be able to focus more on also improving deceased donor rates,

which have remained relatively low in New Zealand for the last decade at about 40 per year.

“Increasing deceased donor rates would boost renal transplant numbers even further. We want as many people as possible who need a transplant to be able to receive

an organ. Organ transplantation saves lives, and reduces expensive health care costs, such as dialysis.”

The cost of looking after a patient with a kidney transplant is about a third of that compared to a patient on dialysis, Dr Cross says.

From our Medical Director – Kelvin Lynn

I will be retiring at the end of this year from my job as Medical Director of Kidney Health New Zealand. This provides an opportunity for me to look back on my time working for KHNZ. Despite moves of offices and the effects of the earthquakes of 4 September 2010 and 22 February 2011 the office team has remained unchanged – Guy, Carmel, Deanne and I.

The organisation has come a long way since I was appointed as the first Medical Director in 2006. At that time Professor John Morton was the Council Chair, we were the New Zealand Kidney Foundation and the aims of the organisation had changed little since its inception in 1979. In 2006, the Foundation had a major emphasis on increasing deceased organ donation, supporting patients with kidney failure and their families and on funding basic research into the causes of kidney failure. The Foundation’s office had moved to Christchurch in 1999 and under the guidance of Guy Johnson, CEO, and Dr Richard Robson, long-standing Board member and Treasurer, the parlous financial state of the organisation had been corrected. The then Council had a distinctly medical membership (I even had a brief stint as Chair in 2007) Council and in my view we did not have strong links with patient support groups, kidney health professionals or the Ministry of Health.

As part of a new focus on early prevention and treatment of chronic kidney disease (CKD) under the chairmanship of David Henderson, the Foundation changed its name to Kidney Health New Zealand and the Rules and Constitution were revised with the guidance of Mr Trevor Roberts. The new name was launched by the Minister of Health, David Cunliffe, at Parliament Buildings on 12 March 2008. In 2007, the Board made the decision to change its research grants policy to focus on funding research that was related to the goals of the organisation. An annual World Kidney Day, starting in 2006, allowed KHNZ to focus awareness of how common CKD is, who is at risk and the links with diabetes, high blood pressure and heart disease. KHNZ activities involved the staff of kidney units, patient support groups and other organisations such as Diabetes New Zealand and the Stroke Foundation. One of the most successful was the regular visits to Parliament to offer kidney screening to MPs and their staff.

By 2009, I thought that we had much improved relationships with kidney units, patient support groups, kidney health professionals and the Ministry and had increased recognition nationally. Guy Johnson, Chief Executive, and Carmel Gregan-Ford, Education Manager, played a large part in these achievements.

The Medical Director became an ex officio member of the key national advisory group on renal services, the National Renal Advisory Board (NRAB). The NRAB launched a Renal Service Improvement programme with the Ministry aimed at: improving CKD management in primary care; increasing rates of renal transplantation; regional coordination in planning to address demand and access; national coordination in renal workforce development and improving information about and for renal patients. KHNZ was awarded a number of contracts by the Ministry of Health to produce web-based consumer information resources as a result of this initiative and the upgraded website has become the primary New Zealand source of information on kidney disease and its management. The website also hosts material from the NRAB, the Ministry and other organisations. KHNZ also produced a popular guide for GPs – Chronic Kidney Disease (CKD) Management in General Practice - and a new booklet for people contemplating treatment for kidney disease – Living with Kidney Disease - which are both used extensively by health professionals and patients.

Kidney transplantation has always been an important issue for KHNZ. Professor Morton and I presented the then Foundation’s submission to the Health Committee on the Human Tissue (Organ Donation) Amendment Bill in 2007. In this we communicated a change in the Foundation’s view that registering organ donors would increase organ donation rates arguing that establishing and maintaining such a register would be complicated, expensive, and unlikely to increase organ donor rates. This view was supported by both the Health Committee and the Ministry. We argued that what was needed was increased community awareness of the benefits of kidney transplantation, an informed community discussion of the social and cultural barriers to organ donation for Maori and Pacific Peoples and investment in training the health staff whose task it is to discuss organ donation with the families of potential donors and obtain consent for organ donation. While a lot has been done to improve deceased organ donation, deceased donor transplant rates have not change over the past decade.

Over recent years there has been greater focus on living donation with KHNZ endorsement of the Private Member’s Bill introduced by Michael Woodhouse, Financial Assistance for Live Organ Donors Bill; funding of research into living donors’ experiences; support for new technologies such as the Kidney Exchange programme and non-directed live donation; and the Five Point Plan developed by the NRAB for the Minister of Health. These initiatives have resulted in increased funding for live donor

kidney transplantation and the establishment of a National Renal Transplant Service.

Research in New Zealand and abroad has confirmed the benefits of home dialysis to patients, families and the health service. New Zealand is a world leader in home dialysis with half of all dialysis patients managing their treatment at home. KHNZ has continued to advocate for the removal of barriers to accessing these treatments.

In 2013, KHNZ held a number of meetings with patient support groups that resulted in the formation of a Consumer Council to provide input to policy and to critique strategic planning. The Board has produced a Strategic Plan for 2014 -17 guided by this feedback that identified the need for KHNZ to be “the national voice for people with chronic kidney disease and their families and the primary source of reliable and relevant information on the prevention and management of kidney disease”. Before the recent general election KHNZ produced a Manifesto, A Blueprint for the Improving Renal Service in New Zealand, incorporating the aims of the Strategic Plan. The Manifesto had seven points directed at increasing transplant rates, improving support for dialysis patients and education of general practitioners and practice nurses on the care of people with kidney disease.

With the new focus on early detection and treatment of chronic kidney disease it became apparent that KHNZ could not achieve its goals without working closely with other similar organisations. We are too small to “go it alone”. Chronic kidney disease is closely linked with diabetes, heart disease and high blood pressure and its detection and management should be linked to the care of these conditions in primary care. KHNZ has thus established links with Diabetes New Zealand, the Heart Foundation of New Zealand the Stroke Foundation and Agencies for Nutrition Action. We also work closely with Kidney Health Australia, Organ Donation New Zealand,

Primary Health Organisations and Parliamentarians. The Ministry has also recognised the need to include kidney disease as one of the group of important long term conditions affecting the community.

In mid 2013, the Board appointed three Honorary Medical Advisors to work with the Medical Director - Doctors Viliami Tutone, Jenny Walker and Colin Hutchison. I am grateful to these three nephrologists for volunteering their time and expertise for KHNZ.

It is not possible for me to do my job without the help and support of many people outside the organisation: notable among them are nephrology colleagues Mark Marshall, Grant Pidgeon, Johan Rosman, Jenny Walker, Ian Dittmer, John Collins, Nick Cross, Murray Leikis, Alastair Macdonald, Suetonia Palmer, Tonya Kara and Rachael Walker (Nurse Practitioner), Dr John Pickering (Scientist), Karen Brown (Radio NZ), Dr Tim Mathew (Kidney Health Australia), Dr Nick Polaschek (Ministry of Health) and the late Professor Sir Don Beaven.

There is still much work to do to improve the detection and management of CKD. The rate of kidney transplantation at 110-120 operations annually has been unchanged for a decade. Five hundred people start treatment for kidney failure each year although this number shows signs of stabilising. The number of people on dialysis has risen from 1,997 in 2006 to 2,469 in 2012. Although the proportion of dialysis patients doing their own treatment at home is high by international standards at 50 percent, it has fallen from 69 percent in 2000.

I am grateful to Dave Henderson and the Board of KHNZ, the other members of the Executive team, Carmel Gregan-Ford, Education Manager and Guy Johnson, Chief Executive, Deanne Hock, Administrator, my nephrology colleagues and the many members of patient support groups for their support and advice over the past eight years.

Kelvin Lynn – “Man for the moment”

Eight years ago KHNZ was at the cross roads with a sound financial base and the trust and respect of patient groups, however it lacked a voice with renal professionals and the relevant government agencies. To bridge this gap Kelvin was appointed as the first Medical Director.

In the 8 years Kelvin has been with KHNZ he has lifted the profile to such an extent that we are now represented at all major renal meetings, consulted by and work with the Ministry of Health on all renal matters. His membership on the National Renal Advisory Board, Australasian Home Dialysis Committee and working alongside our Education Manager, Carmel Gregan-Ford has made significant progress in putting kidney disease in front of New Zealanders be it for CKD dialysis, organ donation or advising on international trends.

Kelvin's commitment to the welfare of people affected by kidney disease is obvious; he passionately supports the



role Kidney Health New Zealand has and he will be missed by us all.

His significant contribution to KHNZ has been appreciated and Kelvin was definitely the man for the moment. On behalf of the Board and staff we thank Kelvin for his contribution and wish him well in his retirement.

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, 15 Thames Street, Christchurch 8013

Thank you for your support

For more information, check out our Facebook page

<https://www.facebook.com/pages/Kidney-Health-New-Zealand/206096806091572>