Sioney Health NEW ZEALAND

Prevention • Support • Research

Summer 2015

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Final word from Guy

Already we are half way through summer, and there has been a lot happening in the office, so in this issue we sadly farewell one CEO but welcome our new one.



Farewell Guy

Guy Johnson retires this month following fourteen years at the helm of Kidney Health New Zealand. He has been an integral part of the organisation, with his business acumen and financial expertise.

Guy has been responsible for ensuring Kidney Health New Zealand's financial viability and sustainability and certainly leaves the organisation in good financial health. From a personal perspective it has been a pleasure working with Guy, his sense of humour, encouragement and support over the years has made our work enjoyable. We would like to take this opportunity to wish Guy all the very best in his retirement. You'll be missed.

From the Board

On behalf of the Board of Kidney Health New Zealand I want to acknowledge the 14 years of work that Guy has put into our organisation. Through all the changes, the financial ups and downs, the comings and goings of different board members, the office relocations, the generous support we have received from benefactors and the difficulties we had for a while getting the ear of government, Guy has consistently been here. Guy has quietly kept the organisation running, organising meetings, giving advice, suggesting strategies, building a great staff team, and working for the future of KHNZ.

For several years Guy has been expressing a wish to retire, but he has stayed on to see us through another phase, and then another. The strength we have to be able to take significant steps forward now, with our latest strategic plan, a growing role in support of kidney patients and families, and growing recognition on the part of government of the value of our contribution, are all due to the groundwork that Guy has guided and helped us lay.

We sincerely thank Guy for his contribution, and wish him well as he heads for a long and healthy retirement.

Dave Henderson KHNZ Chair

Welcome Max

Max brings extensive experience gained from nearly twenty years in senior leadership roles across the health and social services sectors in New Zealand.

Following twelve years as a Presbyterian parish minister, Max worked for a number of years in Church-based management roles – initially with Presbyterian Support Otago, and subsequently as Superintendent of the Dunedin Methodist Mission. Since then, Max has held senior management positions in aged care (both residential and community-based), mental health and palliative care. He has served on numerous not-forprofit boards, and a number DHB and Ministry of Health working parties.

Alongside his Business Studies degree, a postgraduate diploma in Community Development, and a Master's degree in Social Policy, Max is also a Fellow of the New Zealand Institute of Management, and a past member of the Fundraising Institute of New Zealand.

Based in Dunedin, and married to Dr Lorraine Ritchie, a Professional Nursing Advisor with the NZ Nurses' Organisation, their blended family includes five adult children, a cat, and a relentlessly precocious Terrier by the name of Brian.

Max is enthusiastic about his new role with Kidney Health NZ, and both the challenges and opportunities that lie ahead. "While NZ is doing very well in drawing attention to the growing rates of chronic illness, chronic kidney disease seems to be off the radar somewhat," he says. This new position offers an opportunity to further raise the profile of kidney health in NZ, including working with DHBs to increase the rates of home dialysis, and with government to draw attention to the need to increase transplantation rates and support for both kidney donors and recipients."

CEO Update

Six weeks' into this new CEO role and the learning curve shows no sign of flattening out – as should be the case, of course. Life is about always being prepared to discover new things; every new learning only serving to remind us how much we still have to learn.

I'm a 'newbie' to the kidney health environment. In that sense, I'm one of the very people that Kidney Health NZ's latest educational DVDs are aimed at. And having had the chance to preview each one of them, it was a real sense of pride that one of my first official tasks as CEO was to be at the launch of the DVDs by Health Minister Dr Jonathan Coleman in Wellington. What a privilege to meet so many people who had been involved in the making of the DVDs; and what an opportunity to remind the Minister that, while he and his Ministry need to be assured of sound clinical guidance from kidney health professionals, the guidance that Kidney Health NZ – representing the kidney health consumer and family voice - has to offer him and the Ministry of Health, is equally important.

Launched alongside Kidney Health NZ's new DVD resource was the Ministry of Health's chronic kidney disease (CKD) Consensus Statement. While it is encouraging to see an increase in kidney donation rates and a resultant increase in the number of kidney transplants possible, the gap between the number of people diagnosed with (CKD) each year, and

the number of transplants, continues to widen. It is estimated that there are some 200,000 New Zealanders with CKD, with a further one in ten New Zealanders at risk of developing it.

Alongside increasing kidney donation and transplant rates there needs to be much greater emphasis on the role that primary healthcare teams play in the early detection of New Zealanders at risk of developing CKD. And that is the key thrust of the CKD Consensus Statement. Representing a broad range of parties (including Kidney Health NZ, diabetes specialists, renal physicians, GPs, nurses and Ministry of Health personnel) the Consensus Statement firmly places the prevention of CKD alongside its treatment as a national health priority.

I mentioned my comment to the Minister that he and his Ministry need to hear the voice of kidney health consumers and their families – and that Kidney Health NZ has, as part of its mandate, advocating on your behalf. Perhaps that was a little arrogant of me – not in terms of challenging the Minister in that way (it's their job to be challenged!), but that Kidney Health NZ should claim to speak on your behalf. To the

extent that we can claim such a role, it is absolutely critical that our voice is informed by your own. For that reason, one of the priorities I have set for myself in this new position is to meet with as many of the kidney health support groups around the country as I can.

My ability to do so, of course, will be entirely dependent upon your willingness to invite me! Hopefully, by the time you read this Newsletter, you will have received either a letter or an email from me, with an offer to meet with your local or regional support group in the near future. Nothing special. Just me, dropping in on one of your regular meetings, to listen. To hear what's important to you. To hear the stories you want told, the concerns you want raised. To hear how Kidney Health NZ may better support you and resource you in the vital role you play in your local communities. I'd love the opportunity to have such a conversation with you. Equally, please feel free to contact me directly either by email (max@kidneys.co.nz) or via Kidney Health NZ's free-call number 0800 KIDNEY (543 639)

Nga mihi nui **Max**

What's New In The KHNZ Office?

Where do I start?

As well as Max starting as CEO, he has been joined by Dr Colin Hutchison who is our new Medical Advisor. Colin is working as a nephrologist in Hawkes Bay, where he will continue to be based. Look out for his profile in the next newsletter. Joining Max and Colin is a new board member Nick Polaschek from Wellington. Nick brings a wealth of experience and knowledge to the Board, both as a renal nurse and more recently working as Senior Project Manager CVD diabetes Long Term Conditions at the Ministry of Health.

We have also just moved into our very own office space, it has the benefit of plenty of parking, being located in the busy Bishopdale shopping centre and we think the new signage is eye catching, leaving no doubt as to our role. We welcome visitors and will be offering free kidney health checks to our new neighbours soon.



Kidney Health NZ new office Unit 7, 337 Harewood Road, Bishopdale, Christchurch. PO Box 20072, Bishopdale, Christchurch 8543

Hero. Legend. Brother: 24 Hours Of Nduro

Rotorua mountain biker, Lance Tavinor was all those things and more when he took on the solo category in the 24 hours of Nduro in the Whakarewarewa Forest over the weekend. With \$5 from every entry going to Kidney Health New Zealand, he was riding for a cause close to his heart. His older brother, Grant, is ill with kidney disease. Lance is undergoing rigorous testing to see if he is a suitable donor. He also put himself through one of the most challenging tests for a mountain biker, when he started the Nduro at midday on Saturday. "He went out a little fast with his race face on at the start," said his pit crew boss, Benny Devcich who works with him at local bike shop, Cyclezone. "But he settled into a good rhythm as night fell." The weather and riding conditions were perfect. After one of the driest and hottest Januarys on record, there was rain on Friday night and the race started in a refreshing drizzle. Lance was still going strong as dawn broke on Sunday morning. He passed the 300-kilometre mark on the demanding 14-kilometre course as the clock ticked down to midday.

At the same time, multiple 24 Hour Solo world champion, Jason English, from Australia confirmed his favouritism to win the men's race, with the New Zealand title going to David Rae in second place.

Another Australian, Liz Smith, was first over the line in the hard-fought women's category with Kiwi, Anja McDonald, riding a brilliant race to take the women's title.

Then the focus turned to Lance's last lap. He was cheered on his way by a big crowd of supporters and arrived back to an even bigger round of applause. "I had to ride that last lap upright," he said as he enjoyed a post-race beer. "My back was so sore I couldn't lean in to the handlebars." He took a long swig and then held out his hands. They were bruised and calloused. "Sleep next," he added with his trademark grin.

Thank you Lance for choosing to support Kidney health New Zealand and we wish you all the very best for both you and your brother.



Walking For Kidneys

Congratulations on a mammoth effort Ros and Hugh, who are now back home after six months raising awareness about live kidney donation.

A wonderful way to start the New Year when we were fortunate enough to be able to spend time with Ros and Hugh during their stopover in Christchurch, a group of us cycled around Hagley Park on the first day of the year together with the Walking for Kidneys duo.

Kidney Transplant Donors And Recipients Energetic Campaigners

A Wanaka father and son and a Whangarei husband and wife who were previously strangers connected over kidney transplant success stories at the weekend.

Ros and Hugh Cole-Baker are travelling the length of New Zealand, loosely following the 3000km Te Araroa trail, to raise awareness of the need for more live kidney donors and help reduce the waiting list for those needing a kidney.

Mrs Cole-Baker gave her husband one of her healthy kidneys 15 months ago, after he spent 10 years struggling with kidney disease, resulting in renal failure and the need for dialysis.

''I just wanted him well so it was an easy decision,'' she said.

Rob Johnston, who received a live kidney donation from his son Richie just over three years ago, read about the Whangarei couple's travel plans in The Renal Messenger and got in contact, inviting them to stay at his bed and breakfast when they passed through Wanaka.

The Otago Daily Times caught up with the Cole-Bakers and Johnstons on Saturday after they returned from a bike ride and walk up Mt Iron together.

The Cole-Bakers said they were inspired to embark on their ''Walking New Zealand for Kidneys'' challenge by walkers on the Te Araroa trail, which goes ''right past our place''.

They wanted to show others that being a donor 'wasn't going to be a huge setback and also there was life after a transplant", Mr Cole-Baker said.

Since leaving Cape Reinga in September, Mrs Cole-Baker has been travelling south mainly on foot and by mountain bike, while Mr Cole-Baker supports her efforts from a campervan.

He has joined her on some of the cycle legs though, after buying a mountain bike in Palmerston North.

The couple said they had enjoyed many "humbling" and "incredible encounters" with people along the way who wanted to hear their story and share their own experiences - such as the Johnstons.

'So the big advantage of a live donor, if it's compatible, is it's within a year or so."



Richie and Rob Johnson pictured here with Hugh and Ros.

Mrs Cole-Baker gave her husband one of her healthy kidneys 15 months ago, after he spent 10 years struggling with kidney disease, resulting in renal failure and the need for dialysis.

On Saturday, the four new friends all reported a return to full health as a result of their transplants.

"We couldn't be doing something like this [travelling New Zealand] otherwise," Mr Cole-Baker said.

"'We'd have to bring a [dialysis] machine with me and I wouldn't have had the energy anyway."

Rob Johnston's assessment of his transplant was simple.

"My son saved my life."

Snowboard instructor Richie Johnston said he had now adopted a healthier approach to life, in terms of eating the right things and staying active, and giving a kidney to his father had not slowed him down.

"It doesn't stop me doing what I love to do."

People could wait up to eight years for a compatible kidney from a deceased donor, which was ''too long for some'', Mr Cole-Baker said.

"So the big advantage of a live donor, if it's compatible, is it's within a year or so."

The Cole-Bakers headed to Arrowtown and Queenstown after leaving Wanaka on Saturday afternoon.

They expect to complete their journey next month with a group of Invercargill people on dialysis who will walk with them to the finish line at Bluff.

lucy.ibbotson@odt.co.nz [2]
Source URL (retrieved on 11/02/2015 - 12:06): http://www.odt.co.nz/news/queenstown-lakes/330406/kidney-transplant-donors-and-recipients-energetic-campaigners

World Kidney Day – Thursday 12th March 2015



World Kidney Day 2015 - Press Release

Celebrated every year on the second Thursday in March, World Kidney Day (WKD) is a campaign dedicated to raising the profile of kidney disease, which affects 10% of the adult population worldwide. It aims at increasing awareness of the importance of our kidneys to our overall health and to reduce the frequency and impact of kidney disease and its associated health problems worldwide.

WKD Objectives

- Raise awareness about our "amazing kidneys" highlight that diabetes and high blood pressure are key risk factors for Chronic Kidney Disease (CKD).
- Encourage systematic screening of all patients with diabetes and hypertension for CKD.
- Encourage preventive behaviours.
- Educate all medical professionals about their key role in detecting and reducing the risk of CKD, particularly in high risk populations.
- Stress the important role of local and national health authorities in controlling the CKD epidemic. Health authorities worldwide will have to deal with high and escalating costs if no action is taken to treat the growing number of people with CKD. On World Kidney Day all governments are encouraged to take action and invest in further kidney screening.
- Encourage Transplantation as a best-outcome option for kidney failure, and the act of organ donation as a life-saving initiative.

If detected early, Chronic Kidney Diseases can be treated—thereby reducing other complications and dramatically reduce the growing burden of deaths and disability from chronic renal and cardiovascular disease worldwide.

In New Zealand the number of patients being treated for kidney disease has steadily risen since dialysis treatment began. For example in 2000 there were 1336 patients on dialysis compared with 2584 at the end of 2013, representing an increase of 84% in 12 years. About half of these patients have diabetes as the cause.

This year's campaign focused on raising awareness about this issue, while continuing to encourage the importance of living more healthily. Taking steps to live a healthy lifestyle drastically helps to reduce risk of kidney disease, and its progression to kidney failure.

New Zealand statistics (as at Dec 31st 2014)

- Number of patients receiving dialysis 2584
- Number of people with a functioning kidney transplant
 1568
- Number of new patients with End Stage Kidney Disease
 546
- Half the patients presenting with End Stage kidney Failure were as a result of diabetes
- Half of those patients receiving dialysis were being treated at home.
- It is estimated that there are about 210,000 adult New Zealanders with Chronic Kidney Disease.
- The cost to the health system of dialysis for an individual ranges from \$30,000 to \$60,000 per year.

People who are at the greatest risk of developing kidney disease include both Maori and Pacific people, those aged over 50, those who smoke, have high blood pressure or diabetes, and those with a family history of kidney disease. CKD is easily detected by the measurement of blood pressure, a simple test for protein in the urine and a blood test to estimate kidney function. All of these tests are readily available in general practice.



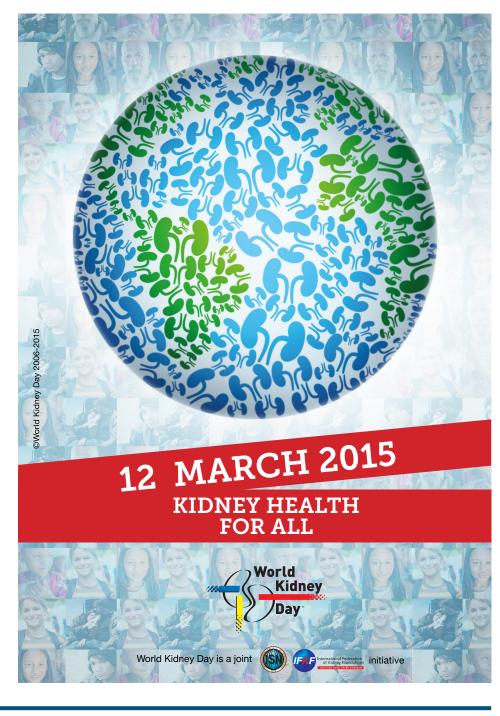
From the World Kidney Day committee

This year's theme "Kidney Health for All" makes this call to action even more meaningful since it also helps highlight a number of key issues and challenges in tackling Chronic Kidney Disease in vulnerable populations: poor water hygiene, lack of hydration and unhealthy choice of beverages.

Studies have shown that people drinking sodas on a daily basis have higher risk of developing some level of CKD. This is because soft drinks increase the level of protein in the urine, which is considered an early marker of kidney damage. By inviting everyone to raise a glass of water for

their kidneys on World Kidney Day, we would also like to highlight this issue and encourage everyone to make the healthy choice of drinking water instead of soft drinks. To learn more about World Kidney Day and Kidney Health New Zealand's activities visit www. kidneys.co.nz or call 0800 543639 (KIDNEY)

Studies have shown that people drinking sodas on a daily basis have higher risk of developing some level of CKD.



Audio-Visual Resources

On World Kidney Day these resources were officially launched at a function hosted but the Minister of Health the Honourable Dr Jonathan Coleman MP, in Bowen House, Wellington. These patient focussed resources have already been used by pre dialysis educators around the country and the feedback has been very positive. We have already had enquiries from overseas requesting use of the graphics, so a real testament to their value as an education tool. These can be found on our website at:

www.kidneys.co.nz/Patient-Information/Audiovisualeducation-resources



Memory sticks styled to look like a credit card have been produced and have been distributed to renal units nationally. The Samoan and Tongan versions are now available also.

Our thanks in particular go to Murray Fergusson from Clearcut Productions, who has gone the extra mile with his dedication and commitment to this project to ensure a high quality resource was produced. Also a big thank you to the staff and patients from the Wellington Renal Service at Capital Coast District Health Board, who were involved in the filming, your participation is very much appreciated. These resources will be of so much benefit to not only kidney patients and their families but for anyone wanting to understand more about kidney disease and its treatments.

KHNZ Fundraising

I would like to acknowledge the ladies who do our telephone fundraising for us. Fiona, Gina and the team do an amazing job helping to raise funds to enable us to continue our work. With no government funding this is a vital part of keeping KHNZ as the leading organisation in New Zealand as:

- The national voice for people with kidney disease and their families
- The primary source of reliable and relevant information on the prevention and management of kidney disease.
- Identifying and funding research to support KHNZ's objectives.
- They are based in North Beach, Christchurch. The staff contacts businesses during the day and the general public in the evenings to request donations to KHNZ.

The phone numbers to donate via our tele fundraising line are 0900 777 10 for \$10.00 and 0900 777 20 for \$20.00.

Fond Farewell from Guy

As I sign off after fourteen years as Executive Director for Kidney Health NZ, I look back on a remarkable period of growth for the organisation.

Twelve years ago a chance meeting with Dr Richard Robson opened the door to a whole new world to me. Richard was a Board member of the Kidney Foundation of NZ, who were transferring their office to Christchurch. As Executive Director of the Canterbury Medical Research Foundation, with an office in the Christchurch Public Hospital, I offered to host their first meeting. I attended this meeting and was appointed Secretary and then Executive Director, a position from which I retired last month. Eighteen months later we appointed an Education Manager (Carmel Gregan Ford), and re-established our commitments to the many Patient Support Groups

around New Zealand. Nine years ago we appointed Professor Kelvin Lynn as our first Medical Director who was instrumental in bridging the gap between the Renal Professionals, Ministry of Health and the Patient Societies. To re-position the Foundation as a viable organisation I invited the CEO from Kidney Health Australia to visit us and make recommendations as to the best way to move forward, we revised our constitution, changed the name to Kidney Health NZ.

Over the years we have set up a Patient Consultation Group and prepared information on all aspects of kidney health for the Ministry of Health's website. We have visited many and varied organisations from Parliament to large corporations testing staff for blood pressure and early signs of renal failure. We have

organised Kidney Awareness Weeks, including National Drink Water Week, and A Mad Butcher promotion covering important topics relevant to kidney failure. The many calls for the 0800 support telephone line, the constant battle on behalf of patients for transplants, and the many other problems faced by patients and their families has given me a better understanding of the challenges they face in their daily lives.

Thanks to Carmel, Deanne and Kelvin for all their support over the years. It is satisfying to leave the organisation in such a sound financial and operational position. Thank you to all the wonderful people I have had the privilege to meet on this journey. Wishing you all the best for the future.

Guy Johnson



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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 Please return this form to: Kidney Health New Zealand, PO Box 20072, Bishopdale, Christchurch Thank you for your support

For more information, check out our Facebook page https://www.facebook.com/pages/Kidney-Health-New-Zealand/206096806091572