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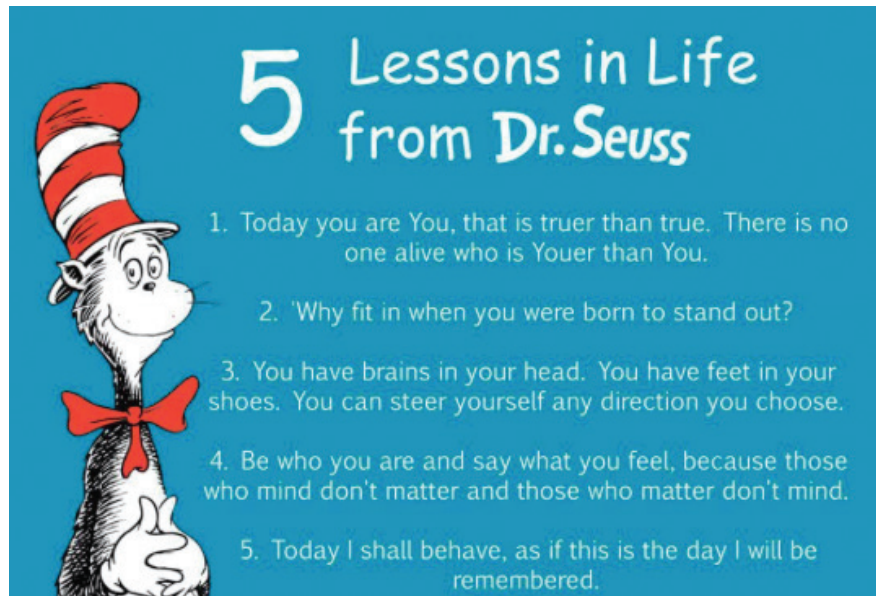
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From the CEO



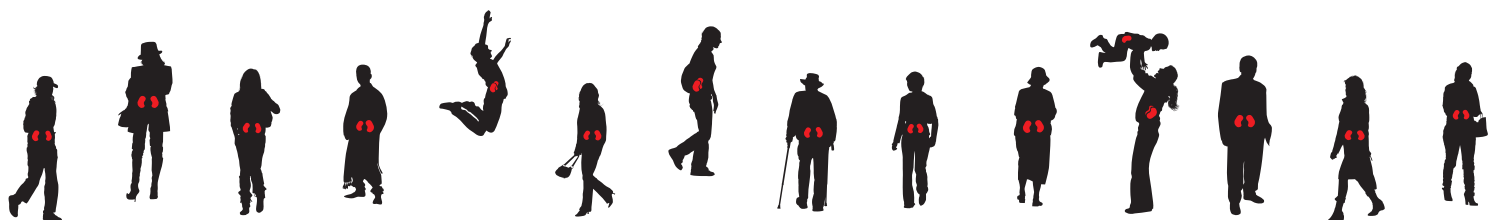
Welcome to the Winter Edition of our newsletter!

It has been a busy couple of months and I can't believe the longest day has been and gone and we are now rapidly heading towards warmer months.

In the meantime there has been a lot of work happening in the area of Deceased Organ Donation, as many of you will be aware there is currently a consultation document "**Increasing Rates of Deceased Organ Donation**" available for comment, with submissions due at the end of July.

I'd encourage you to have a look at the document if you have an interest in this area.

<http://www.health.govt.nz/publication/increasing-rates-deceased-organ-donation-consultation-document>



Chronic Kidney Disease Education Modules

Other work nearing completion is the Management of Chronic Kidney Disease in Primary Care education package we have been working on. Following consultation with a number of experts we will have four modules available for practice nurses and three modules for general practitioners; already there has been a lot of interest in these with several education sessions booked in around the country over the coming months. We continue to work alongside BPAC as they continue to launch their electronic tool designed to assist GPs in identifying at risk patients in their practices. Both projects are aimed to reduce the numbers of patients reaching end stage kidney disease by slowing down the progression of kidney disease.

Renal Society of Australasia Annual Conference



Recently I attended the Renal Society of Australasia Annual Conference held in the Gold Coast, where I presented on the Chronic Kidney Disease Consensus Statement and its recommendations, this was preceded by two very interesting presentations by Debbie Fortnum from Kidney Health Australia. Debbie talked about their new App “My Kidneys My Health” which can be downloaded for free on personal devices, it is very good with lots of interesting information about how the kidneys work and what kidney disease means and how to look after your kidneys. This is a great tool and certainly an indication of the advances being made with digital technology in health.

In another presentation – “**What’s New in Transplantation**” by Dr Scott Campbell, he talked about the Paired Kidney Exchange Program in Australia which commenced in 2010, since then there have been over 150 transplants performed. A computer generated search is carried out every three months to check for any potential matches from those signed up to be live donors in the Paired Exchange Program. Developments in this area include, the opportunity for Hepatitis BcAb positive donors to be used, as transmission of this virus in these cases is almost nil, report cards to identify patients who never come up for a potential match – this will flag the possibility that the criteria may be too difficult and therefore enable a closer look as to the reasons for the wait and what could be done to improve the chances of a successful transplant. Currently work is underway for New Zealand to join the Australian program within the next year.



🔗 Check out...



Living With An Organ Transplant – Facebook page

The idea of this group is to provide a safe, non-judgmental forum for people who have had an organ transplant.

It is hoped this will become a place that enables members to discuss freely their experiences and a place to gain hope, strength and support from other members who have had a transplant.

This page has been created by Carmel from KHNZ who recognised the need for people post-transplant to have a forum like this, but the aim for the group is for it to be taken over and run independently by its members, below are the links to this page and the KHNZ page.

<https://www.facebook.com/groups/1032068216875803/>

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

🔗 Making the news ...



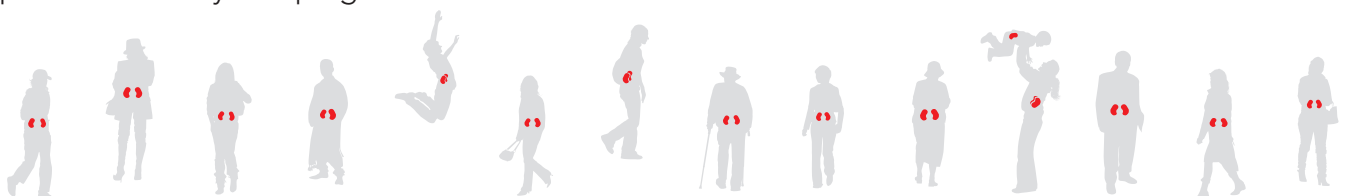
Another option to assist in raising deceased organ donation awareness

Apple is adding the option to enroll in the US national donor registry by tapping a button within the iPhone's Health app, which can be used to manage a variety of health and fitness data. The software will come to all US-based iPhones when the company updates its mobile operating system this autumn.

The move follows action by the US government to attempt to reduce long waiting lists for organ transplants, in which someone is added to the list every 10 minutes and 22 people die while waiting for life-saving transplants every day.

One initiative will see greater automation in the donor and matching service, and increased connectivity with transplant centres, which it is hoped will speed up the matching process to get donor organs to more patients in less time. Almost \$200m (£150m) has also been allocated for research into next-generation manufacturing techniques for tissue creation and repair, which could result in organ replacement.

Apple is not the only technology company that has pledged to aid in driving organ donor registration. Facebook, Google and Twitter have also pledged support to develop new tools and public advocacy campaigns.



Queens Birthday Honour



*KHNZ congratulates Tom on a well-deserved recognition of his service, particularly in the area of renal research, where he has had more than 14 papers published in the renowned *Kidney International* publication.*

MILLER, Dr Thomas Ernest (Tom)
For services to medical research

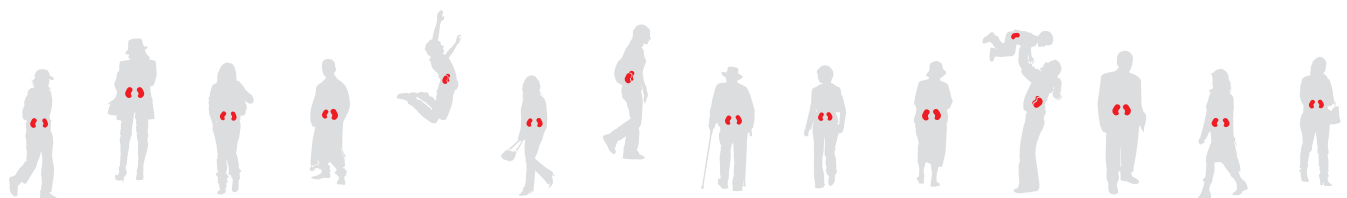
Dr Tom Miller has contributed to medical research for 60 years and has published more than 140 works.

Dr Miller played a key role in the 1960's in the development of the research platform required to establish a School of Medicine in Auckland, focusing on kidney disease, specifically pyelonephritis. His studies of the disease over 30 years were published in many top ranked medical journals and led to overseas collaborations. He joined the University of Auckland in 1994, where he is now Emeritus Research Fellow in the Department of Medicine. From 1994 to 2001 he was Scientific Secretary to the Neurological Foundation of New Zealand, during which time he overhauled the grant processing procedures to reflect a more open and fair peer-review process. His systems are still in use today. He also took up a position with the Multiple Sclerosis Society of New Zealand to help them establish a research programme. In the 2000's he focused on the field of infection control and his resulting analysis and publications saw him recognised as a world expert in the field and has resulted in significant change in infection control practice in hospitals around the world. Dr Miller is currently a member of the Auckland Medical Historical Society.

Tom Miller has been involved in biomedical research for the last 45 years. He holds dual Doctorates in Medicine and Science from the University of Auckland. His involvement in medical research began with the appointment as the third Isaacs Research Fellow in the early 1960's following in the footsteps of Drs Robin Irvine and John Scott.

Irvine, Scott, Miller and Royce Farrelly formed the nucleus of the research arm of the Medical Unit at Auckland Hospital under the direction of Dr JDK (later Professor) North. Tom's research on factors leading to chronic renal failure quickly gained international recognition and, over the years, led to the publication of 140 peer reviewed papers including three in the revered *Journal of Clinical Investigation*.

Recently Tom co-authored a history of Medicine in Auckland between 1960 and 2000 with David Richmond and Judy Murphy. Away from the laboratory his interests have been on the water. The sailing log of his yacht, *Fantasy*, recently turned over 25,000nm mostly carried out single-handed with adventures both locally and in Tonga, Fiji and Tahiti and the Whitsunday Island.



Personal Experience as a Living Kidney Donor – Paul Green

I'm sharing my experience as a kidney donor to encourage anyone with two healthy kidneys to consider donating one. This is just my own experience which may or may not apply to you, so please take from it what you will.

My motivation to become a kidney donor was firstly through understanding how drastically kidney failure impacts people's lives. I found out there are hundreds of Kiwis just like me waiting for a kidney donation and many actually die before one becomes available. I also learned the rest of us with two healthy kidneys actually only need one to maintain full health. Seemed like a no-brainer really.

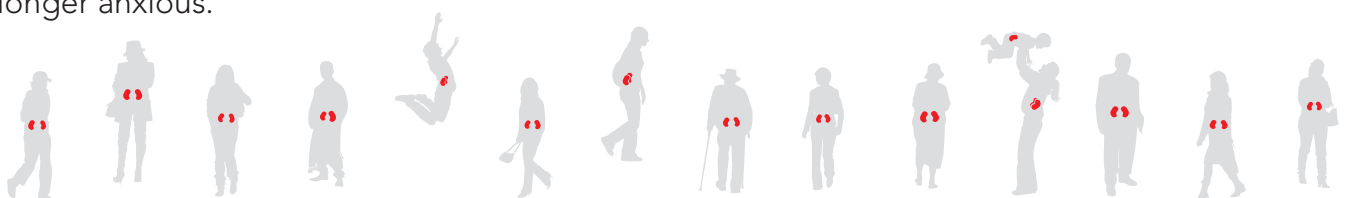
Being a "weekend warrior" endurance athlete I did more research to be totally satisfied this wasn't going to compromise my own long-term health and lifestyle. I also discovered the surgical procedure was laparoscopic, meaning less time off work and faster recovery, but still something to consider. I was training for Ironman at the time so this would need to be factored in. (Little did I know the whole process of tests and interviews was going to take over two years before my donation could proceed.)

Armed with all the facts it still seemed like a no-brainer – for others! This wasn't an easy decision for me. Other than a minor procedure as a child I had never been admitted to hospital before, so there was fear of the unknown. I knew this decision could effectively give someone their life back, but I didn't know who that someone was, so there was no emotional connection. I didn't know anyone else who had donated a kidney, my wife was concerned about my health and what would happen if one of the kids needed a kidney and my friends couldn't understand why I was even considering it. In the end I just knew it was the right thing for me to do and then it was just a matter of finding the guts to commit.

Once I applied, the whole "working up" process seemed to drag on and on. I'm not critical of the steps taken to make sure I was a suitable donor, but as the months slipped by between appointments it certainly tested my patience and I had to ask myself why I was even doing this.

Finally all the tests were completed and I was given a choice of dates for surgery. I was fortunate to have not taken sick leave before so I had a healthy balance to draw on. I checked into hospital the day before surgery. Being perfectly well, I felt like a bit of an imposter and the nurse kindly let me slip away with my wife to have dinner out.

I didn't sleep too well due to noise from other patients and had mixed feelings of anxiety and anticipation. Suddenly I realised the recipient of my kidney would be being prepped at the same time and I felt a real connection and sense of calm. I can't really describe that feeling, but I was no longer anxious.



Next thing I woke up in a haze of anaesthesia. The only thing that sticks in my mind was asking the surgeon how the recipient had responded and he replied: "It's like night and day." I still felt doped up, there was a dull ache from the surgery and I was bloated as they had pumped a whole lot of air into my abdomen for the surgery, but I felt great! I remember the next morning listening to my iPod on shuffle and on came Fix You by Coldplay. I'm not normally an emotional person, but I just started crying and just felt an amazing sense of achievement.

I think I was discharged the day after surgery, once normal bowel and urine functions resumed and I was able to walk around ok. Recovery was pretty quick; back to my office work the following week. The clinicians encouraged activity as long as it felt right and I really appreciated that. I was careful not to do any lifting for a while, but I was able to jog again after a couple of weeks. Within three months I was back completing the Lake Taupo Cycle Challenge and a half Ironman the following month. My rapid recovery was probably helped by having a good level of fitness beforehand and working within my limits.



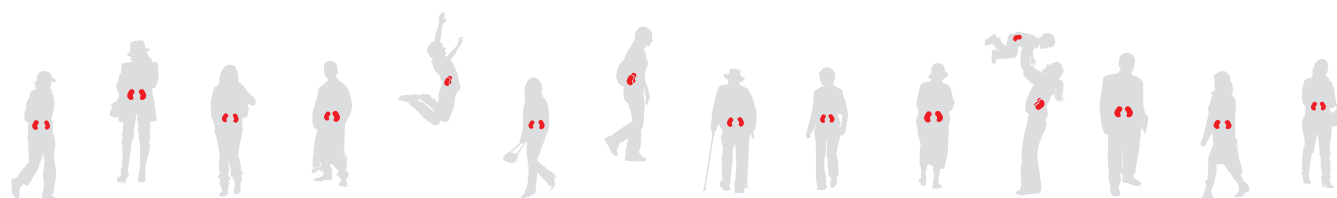
That was 2½ years ago. I get an annual check-up to make sure everything is alright. Apparently there is nothing in my test results that would indicate I only had one kidney and I certainly don't feel any different. My main scar which ran from my belly button to my pubic hairline and three small scars on the side where the instruments went have all disappeared.

I often think of my kidney recipient and hope they are still well. The great feeling I had straight after surgery is still with me from time to time and that's like an unexpected bonus from the whole experience. Like I was satisfied I wasn't going to be any worse off, but I never imagined being a donor was going to be such benefit to me. I don't want to sound flippant because being a kidney donor still involves surgery under a general anaesthetic, but reflecting on it now that just seems like a minor inconvenience in the greater scheme of things.

I consider myself a proud Kiwi. I like the values of courage and compassion that underpin our staunch image and our willingness to lend a hand in tough times, no drama. But I'm not proud that we have one of the lowest organ donor rates in the western world. So Kiwis just like us, even legends among us, continue to suffer and die needlessly.

This is something we can fix. By applying the same courage and compassion that helps define us as Kiwis, each of us has the opportunity become a living legend to someone close, or someone distant.

Paul Green





Kia ora tatou

I'm writing this a couple of days before I head away on holiday for a few weeks.

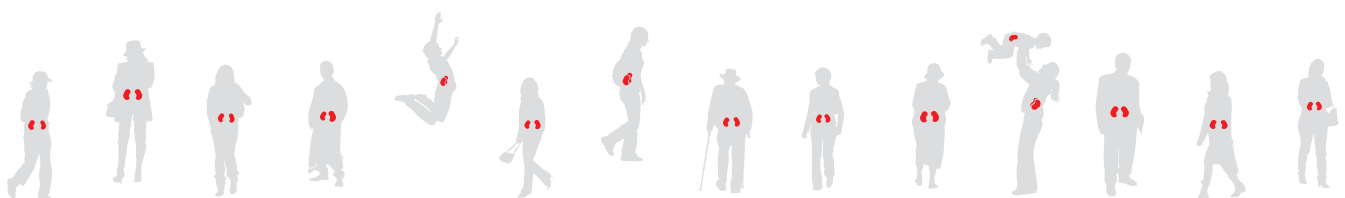
But I wanted to share a few thoughts with you before I go.

One of this morning's emails was an invitation to attend the AGM of the Christchurch Kidney Society later this month. Unfortunately I'll still be away at that time – but it is still wonderful to receive any such invitations to meet with kidney societies and support groups around the country. It really does serve to ground and focus the work that we, as a Kidney Health NZ team, undertake with you and on your behalf.

On a less positive note, I had the opportunity to attend a couple of months ago the opening of the new Toto Ora Dialysis Unit in Mangere, South Auckland – an innovative public-private partnership between Counties-Manukau DHB and Europe-based dialysis provider Diaverum. It's a great facility, and adds capacity for up to a further 30 dialysis chairs. However, the disturbing facet of the opening ceremony was the speech given by the Minister of Health, Dr Jonathan Coleman. After congratulating all the various parties involved, he went on to praise the government's Diabetes Strategy, implying that the opening of the Mangere Dialysis Unit was further evidence of the Diabetes Strategy's success:

“The Government is implementing a number of initiatives to prevent diabetes and to ensure those living with the disease lead healthier lives. The national diabetes plan was launched in November 2015, and the initiative Healthy Families NZ is being rolled out in ten communities.”

Nowhere in his speech were the words 'kidneys' or 'renal' used. Unquestionably the Health Minister and his Ministry are to be commended for the attention that is being given to reducing NZ's rate of diabetes – as they are to be commended for the initiatives they are currently taking in terms of earlier identification and treatment of chronic kidney disease, and lifting levels of both live and deceased organ donation and transplant. It has, however, been of real concern to Kidney Health New Zealand to learn that other key aspects of renal care such as dialysis, have been dropped from the Ministry's Long-Term Conditions work programme. It is apparently considered by the Minister and his Ministry that the work they are doing in terms of prevention at one end of the spectrum and transplantation at the other end – along with the progress being made in terms of diabetes – is enough.



I beg to differ. On behalf of Kidney Health NZ – indeed on behalf of the more than a thousand renal patients whose need for dialysis has nothing at all to do with diabetes – I have raised this matter directly with Dr Coleman. His initial reply, I have to say, has been less than encouraging – reiterating the above perspective that what the government is doing in terms of earlier intervention and transplantation and diabetes is sufficient. Rest assured, I will be looking to further press the matter with the Minister on my return from leave.

To close on a more positive note, I enjoyed attending a seminar put on by Otago University's Renal Research Network yesterday, where some of their latest research was being presented. It was good to be able to establish a link between Kidney Health NZ and the network, and to discuss further ways in which we could possibly partner with the network in the critically important work they undertake.

It made me realise that one of the key ways such a small organisation as Kidney Health NZ could nevertheless support such important research work is by advocating for it – especially to the Ministry of Health and Government.

In this way, the research 'agenda' could be increasingly set by the likes of the Renal Research Network – working at the 'coalface' with renal patients and their families – rather than being dictated by Ministry funding and policy.

Take care. Keep warm. I look forward to reporting back to you on some of these issues in future editions of our Newsletter.

Nga mihi nui

Max

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.