

IN THIS ISSUE

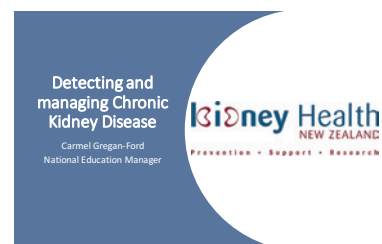
KHNZ news • From the CEO • Walk of a lifetime • Sandra's story
 • Financial Support for Live Organ donors • World Kidney Day 2017

Welcome to the Summer Edition of our newsletter!



Welcome to 2017, we hope it will be a happy and healthy one. As you can see we ended the year in esteemed company at the Annual Renal Society of Australasia symposium held in Auckland at the end of October. Nigel Latta, well known Clinical Psychologist, presented a humorous and thought provoking session identifying strategies for successful outcomes which promote and encourage self-care for patients with a chronic condition. The symposium was well attended and provided a real showcase of how New Zealand renal care is progressing.

The last part of 2016 was a busy one for KHNZ with completion of the Chronic Kidney Disease Education in Primary Care Programme. The modules are ready to go and I was able to distribute some USB sticks containing these at the Nephrology Conference in Whangarei in October. The Information Pack is printed and will be distributed within the next month to all Primary Care Practices throughout New Zealand. We look forward to reporting back on the number of requests for education sessions received following this. The CKD Summary Guide for General Practice is currently being revised and should be completed within the next month also.



Holiday Dialysis (now known as Away From Home (AFH) dialysis) has been a contentious issue over the last few months as it was discovered that some Australian and NZ units were charging patients for treatment when visiting their units. The National Renal Advisory Board and KHNZ have been proactive in trying to ensure consistency throughout NZ, with a letter going to all dialysis units outlining the reciprocal agreement between Australia and NZ that the provision of dialysis is free. There still remains some discrepancy around this, so this still remains a work in progress.

The announcement that there was unanimous cross-party support for the Compensation for Live Organ Donors is wonderful news and there is more about this later in the newsletter.

The theme for World Kidney Day is "Kidney Disease and Obesity" "Healthy Lifestyle for Healthy Kidneys" after consulting with the renal units throughout the country - those that replied were keen on the idea of a walk/run type event to raise awareness. This is a change from taking blood pressures and urine tests in workplaces. We encourage anyone who is keen to raise awareness of kidney disease to get a group together to participate in the local fun walk/run events that are happening in March around the country. We have tee shirts available, further information and a picture can be found later in this newsletter.



From the CEO



Kia ora tatou.

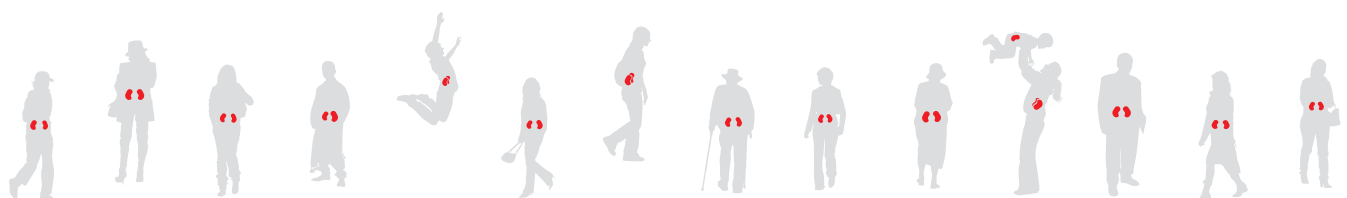
Well, 2016 proved to be quite a year for Kidney Health NZ, kidney patients and their families, organ donors and transplant recipients alike. There were a number of significant 'wins' – most notably the passing of the Compensation for Live Organ Donors Bill into legislation at the end of last year.

But let's not forget other progress made. Alongside the Ministry of Health's significant investment in initiatives to raise both deceased and live organ donation rates, last year saw New Zealand's highest number of organ transplants – the culmination of a 69% increase in organ transplants over the past four years.

There have been smaller 'wins' – but important ones nonetheless. As a result of persistent lobbying on the part of both Kidney Health NZ and the National Renal Advisory Board, MidCentral District Health Board (providing renal services to both the MidCentral and Whanganui DHB populations) has undertaken a comprehensive review of its dialysis facilities in Palmerston North, recognised as substandard by any measure. As a result, a strategy has been approved by the DHB that has seen changes in practice, a proposal to establish additional dialysis beds in Levin, and a commitment to upgrading the main dialysis unit in Palmerston North. It is still early days, and Kidney Health NZ remains concerned at the at the length of time the DHB plans to take in redeveloping the Palmerston North facility – but it is progress, and we will continue to monitor the situation and maintain pressure on the DHB to implement the strategy as quickly as possible.

Also remaining in the 'ongoing' category are Kidney Health NZ's efforts to see attention to renal services formally returned to the Ministry of Health so-called Long Term Conditions work programme. As I have written in previous newsletters, Kidney Health NZ thoroughly endorses the commitments made by the Ministry to increasing organ donation and transplantation rates, and to raising awareness of chronic kidney disease in the primary healthcare setting. But it beggars belief that the Ministry currently has no direct line of sight to dialysis services across the country, when this is both the most common and the most expensive modality of care for renal patients. Again, we will continue to lobby both the Ministry of Health and the Minister of Health himself on this matter.

Looking ahead to 2017, clearly there are some challenges and opportunities ahead. In early March, Kidney Health NZ's Consumer Council will again gather in Wellington. While this will be only the third time the Consumer Council – comprising around eighteen representatives of the various kidney support groups around the country – has gathered since its inception in 2014, the Council nevertheless represents a vital means by which Kidney Health NZ ensures our advocacy and representation of kidney patients and their families is authentic.



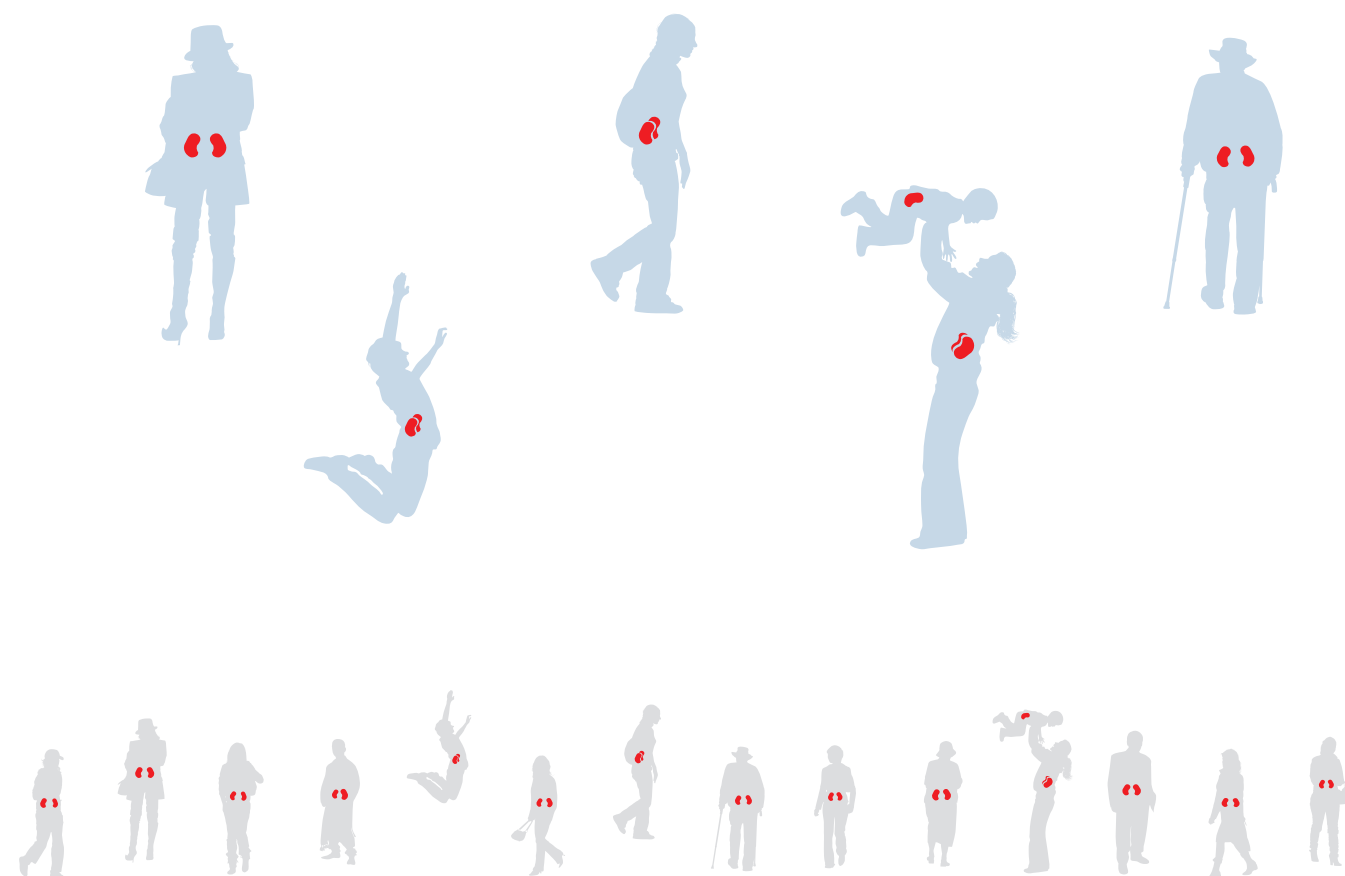
In 2014, the Consumer Council assisted the Kidney Health NZ Board in the development of a Kidney Health Manifesto, presented to all the political parties ahead of the 2014 General Election. That Manifesto identified seven priorities – the achievement of which Kidney Health NZ believed would increase kidney patients' life expectancy and their quality of life:

1. Address the low rates of deceased renal transplantation.
2. Facilitate pre-emptive live transplants.
3. Ensure adequate reimbursement of live donors' expenses.
4. Reduce barriers to home dialysis.
5. Improve support for home dialysis patients.
6. Increase access to "Away from home" haemodialysis.
7. Improve GP knowledge of management of chronic kidney disease.

As you will appreciate, significant progress has been able to be made against most of these priorities. At their March meeting, the Consumer Council will review ongoing progress against these goals and, more importantly, identify further priorities for inclusion in an updated Manifesto for presentation to the various political parties ahead of this year's General Election. This represents a significant opportunity to advocate on behalf of the renal community, and to hold the political parties accountable for their commitment to world class kidney health care in New Zealand.

Ngā mihi o te tau hou. Greetings for the New Year.
May it be a positive and fulfilling one for you and yours.

Max



Walk of a lifetime - Gabi Mae Carrick



I am a 22 year old woman currently living and working in London as a nanny. My Aunty Sandra and her friend recently completed the Camino Frances and inspired me to do something similar.

Therefore this summer I planned to walk the Camino Portugués. It started in Porto, Portugal and ended in Santiago de Compostela, Spain. The total walking distance is 241.9 km, averaging at 24.2 km a day.

Over 200,000 people embark on the Camino walks every year, the reasons varying for everyone. I have a few reasons for doing this, for my fitness, a new adventure, to travel and see a bit more of the world.

However my main reason was to raise awareness for kidney donation.

Polycystic kidney is a hereditary disease that can ultimately cause kidney failure. This runs in my family, in the past it has affected my great grandmother whom died of kidney failure. My great aunt and my grandad were both on dialysis for many years before having transplants. My uncle did not need dialysis as his brother, my other uncle donated his kidney and they both are now living normal healthy lives.

My mother is currently on dialysis and waiting for a new kidney, this to an extent has an effect on how my mother lives her life. My sister and I went to get tested with the intention of donating a kidney to our mother but both results came out positive for polycystic kidneys. Therefore neither of us was suitable for donation.

This is a cause that hits close to home for me so I wanted to do something meaningful in order to help out not only my mother but anyone else who is in need of a new kidney or any organ for that matter.

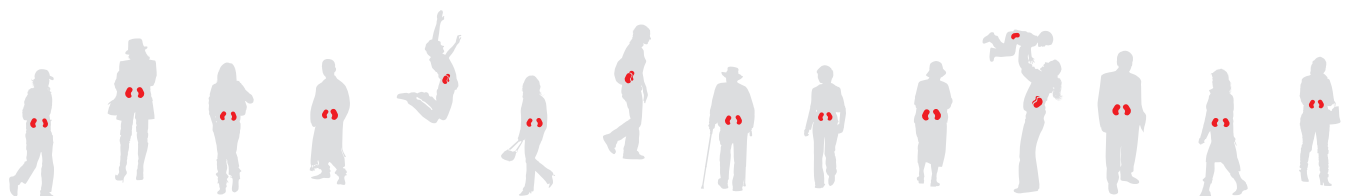
I set up a "go fund me" page for any of you reading this that would like to get involved and help out a worthy cause. Your donations will go towards the Kidney Health New Zealand to help raise awareness and to encourage kidney donations. To date I have raised just under \$2000.00. I have now finished the walk and although I was not able to walk all sections because of blisters and sun stroke I did manage to walk much of the way.



Thank you so much Gabi for your incredible effort, and wonderful donation, you are an inspiration.

https://www.facebook.com/caminoportuges/?ref=page_internal

Recent statistics	2014	2015	2016
Deceased organ donors	46	53	61
Live organ donations	72	74	82



Sandra's story – Making the decision to donate.

The year is 1985.

Organ donation is not on my radar at all. That was all about to change at the speed of a fast moving train.

On the 16th of October, my 4yr old daughter (Kelly) was to start her first day at Kindergarten. I remember feeling so excited and so proud; my girl was off to Kindergarten.

Just before we were to go I suggested she go outside and ask her Dad how she looked. He was working on the car in the driveway, and then within a blink of an eye, Kelly had climbed up the pool table, which was leaning up against the wall.

Bang the table was on the ground with my baby girl underneath.

When we arrived at the hospital, I knew it was bad.

In the Intensive Care Unit I would pray, I went to the chapel, I tried to make deals with God.

When the doctors told me Kelly was brain dead and that she would never have a normal life, I was totally devastated.

Somewhere during that conversation, they also told me that Kelly's kidneys were a match to someone else who really needed them. I knew in that moment that I would give permission for Kelly's kidneys to be taken, as hard as it was to say yes while my heart was completely broken.

At the same time my Mum was having issues with her kidneys so I knew how hard it was for people to have a normal life with kidney problems. Then in 1990 my Mum had a kidney transplant when she received a kidney from my brother.

In the death of my beautiful baby girl two complete strangers got the chance to have a normal life again, as much as that hurts, it also makes me smile.

Had I decided not to donate her kidneys, I would still feel the pain and the loss, so for me it really was a no brainer to make the decision.

I love and miss my baby girl so much, and guess I always will, she did real good work in her short time in this world.

I have a wonderful son David who I love dearly and he has brought joy to my world. Sadly my mum passed away several years ago.

All I have been able to find out about who received the kidneys, is that they were both females who had spent years on dialysis, but after receiving Kelly's kidneys they were able to enjoy life without dialysis.

They both died in the mid 1990's.

I have also wondered why they could tell me this much, and not their names or where they lived, as I often think of them and their families. I wish I did know more.

Sandra contacted me and very kindly offered to share her story. Thank you Sandra for being so brave, and for your generosity in donating your precious daughter's organs.



World Kidney Day – Thursday 9th March 2017

Every year World Kidney Day highlights the importance of Kidney Health and Disease to populations around the world. This year World Kidney Day is focusing on **Obesity and its relationship with kidneys**.

KHNZ Medical Advisor, Dr Colin Hutchison writes:

“Obesity is not a new health problem but unfortunately it is affecting more and more people every year, both here in New Zealand and internationally. Obesity can be defined as an abnormal or excessive fat accumulation that may impair health. In 2014, worldwide over 600 million adults were obese. Unfortunately, here in New Zealand the rates of obesity are very high. The 2015/16 New Zealand Health Survey found that: almost one in three adults (aged 15 years and over) were obese (32%) a further 35% of adults were overweight but not obese.

So why is obesity relevant to kidney health? Well most of us are aware that being overweight increases your risk of heart disease and diabetes. Unfortunately, being overweight can damage your kidneys too.

Obesity can either damage your kidneys directly or cause another problem which can damage your kidneys. When someone is obese, their kidneys have to work harder, cleaning more blood than normal to meet the demands of the increased body weight. The increase in function can damage the kidney and raise the risk of developing Chronic Kidney Disease (CKD) in the long-term. Obesity also increases the risk of developing conditions that can cause kidney damage, such as diabetes and hypertension.

The good news is that obesity, as well as CKD, is largely preventable. Education and awareness of the risks of obesity and a healthy lifestyle, including proper nutrition and exercise, can dramatically help in preventing obesity and kidney disease.

This year World Kidney Day promotes education about the harmful consequences of obesity and its association with kidney disease, advocating healthy lifestyle and health policy measures that make preventive behaviors an affordable option.

Here at Kidney Health New Zealand we will continue our work with primary care teams across New Zealand to help them identify and manage kidney disease early before severe consequences of CKD occur. This year we will have a particular focus on the screening for CKD in individuals with obesity.

On March 9, 2017, we invite everyone to get up and get moving to celebrate their kidneys. “#Move4Kidneys” is a symbolic gesture to remember that kidneys are vital organs and that they should be taken care of. This action urges everyone around the globe, from all cultures and ages, to keep fit and active.

Kidney Health New Zealand has had Tee shirts designed and printed onto a sports type material, staff from renal units from around the country are looking at running/walking in the various Fun run events held annually throughout the country, such as the Round the Bays in Auckland, City to Surf in Christchurch and the Whangarei Hatea Loop. We are hoping to join up with Diabetes groups in some areas as, strength in numbers!”

These Tee shirts are available from the KHNZ office for \$20 each.

Available in small, medium, large and X large.

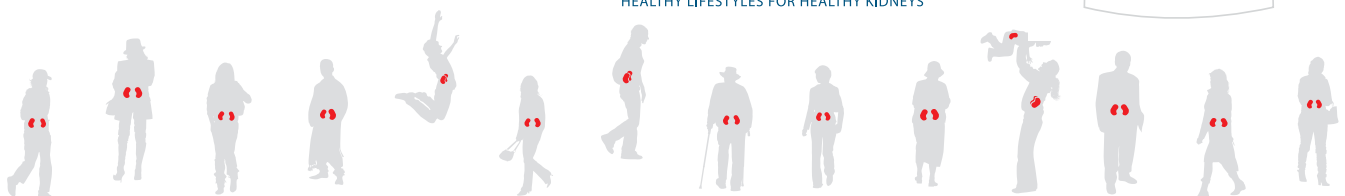
Contact the KHNZ office on 0800 543639 or email info@kidneys.co.nz



FRONT



HEALTHY LIFESTYLES FOR HEALTHY KIDNEYS



Prevention • Support • Research

New Legislation Fully Compensates Live Organ Donors

Royal Assent for the Compensation for Live Organ Donors Bill was given on 5th December last year – the culmination of much work and lobbying by many and (rarely) a result of cross-party political support from the initial Bill's first reading in Parliament back in August.

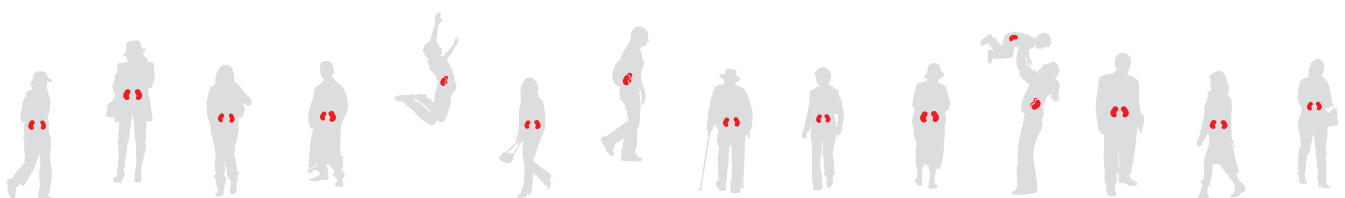
In a media release at the time, Kidney Health NZ chief executive Max Reid commended National List MPs Chris Bishop for sponsoring the Financial Reimbursement for Live Organ Donors Bill (as it was then known) and Michael Woodhouse for his initial introduction of the Bill some six years earlier. Even more encouraging – though not all that unusual at this early stage of a Bill's progress through the House – was that all MPs supported the Bill's referral to the Health Select Committee for further consideration. "But does the Bill go far enough?" Max questioned.

In the months that followed, Kidney Health surveyed past live kidney donors regarding their experience of the current financial assistance regime, then managed by Work and Income NZ. This research was undertaken at the request of the Ministry of Health team advising the Select Committee. We prepared a comprehensive written submission on the Bill, lobbied other organisations in support of our stance, and appeared before the Health Select Committee to present an oral submission.

Kidney Health NZ's submission was that live organ donors should be fully reimbursed for lost income and any associated costs incurred as a result of putting oneself forward as a potential donor. Recent NZ research indicated that, for anyone aged over 35 on dialysis, their life expectancy on average doubles following a kidney transplant. For the more than 1,500 New Zealanders currently living with a donated kidney, their transplant had literally been life-changing. Not only does the transplant make an immeasurable difference for the recipient, but also for their family – who transition from supporting a seriously unwell family member, to enjoying life with a full and active one.

The potential savings to the health system also offered an irrefutable argument in favour of full reimbursement. The saving to the health budget of a 50 year old patient having a transplant as opposed to staying on dialysis for the remainder of their life is more than \$120,000 – even taking into account the fact that this person is likely to live for twice as long post-transplant.

Fundamental to Kidney Health NZ's submission was that any financial assistance to live donors be managed by the Ministry of Health. The current arrangement, where donors have to enrol with WINZ, we found (from our survey) to be both unnecessarily cumbersome and oftentimes demeaning to the donor. It was our view that organ transplants are a health matter, and should be both funded and managed accordingly.



In late October, the Bill came back before the House, with substantial amendments recommended by the Health Select Committee. These including renaming the Bill as *Compensation for Live Organ Donors* (rather than financial reimbursement), lifting the level of compensation from the 80% of lost income originally proposed to full 100% compensation, and transferring the management of the compensation regime from WINZ to the Ministry of Health. Again, the Bill received unanimous cross-party support in the House.

Finally, in late November, the Compensation for Live Organ Donors Bill passed its third and final reading in the House – yet again with unanimous cross-party support. While it will take up to a year to put in place a regime to manage the new system of compensation, it takes effect from 5th December 2016 – the date of the Royal Assent – with any new donors able to backdate their claim for compensation to that date.

“The passing of this Bill effectively removes what is known to be one of the single greatest barriers to live organ donation in NZ,” Max Reid said in a media release at the time. “Until now the level of financial assistance (based on the sickness benefit) has been insufficient to cover even an average mortgage repayment, and the process required to access that support both cumbersome and demeaning. The two major changes that this legislation introduces – increasing compensation to 100% of lost income, and transferring responsibility for the management of that financial assistance being moved from WINZ to the Ministry of Health – will unquestionably remove two major disincentives that exist within the current regime.”

“The challenge now,” Max went on to say, “is to increase New Zealand’s woefully low rate of deceased organ donation.”

That challenge still stands. And, as you will read elsewhere in this newsletter, Kidney Health NZ remains committed to and actively involved in the process of seeing a national strategy put in place that will do as much to increase NZ’s rates of deceased organ donation as we believe the passing of this legislation will do for increasing live organ donation rates.

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.