

# AUTUMN 2016

It certainly feels a long time ago since Christmas. It has been another busy start for the staff at KHNZ with planning for World Kidney Day, and education sessions to a variety of groups.

## IN THIS ISSUE

- KHNZ Update
- World Kidney Day 2016
- Hokitika Wild Foods Festival
- From Our CEO
- Anita's Story / 4 kidney transplants later..
- Renal Vit
- Kidney Transplant News
- National Renal Advisory Board



Serah Lupo and her support crew

## KHNZ UPDATE

Firstly a big shout out to Serah Lupo and her support crew who recently completed the Round the Bays in Auckland. Serah is on dialysis making her effort even more impressive.

Serah is a wonderful supporter of our work and also shared her story on John Campbells Checkpoint show on Radio New Zealand.

In January Dr John Collins and I gave a talk to the staff from Green Cross Medical in Auckland about Managing Chronic Kidney Disease in Primary Care. In March I spoke to nurses from the Auckland Women's Prison on the same topic which was well received, the number of requests to provide education sessions has increased with a number already booked in the coming weeks.

Currently we are working on developing an education package for Primary Care on the management of Chronic Kidney Disease; we have been working on the educational resources, including teaching modules. Special acknowledgement goes to Kidney Health Australia's Kidney Check Australia Taskforce (KCAT), who developed the original packages and has kindly given us permission to modify them to meet New Zealand practices. It is planned to make these modules available to renal units throughout the country and assist with providing education to Primary Care practices throughout New Zealand as we aim to reduce the numbers of people requiring treatment for end stage kidney failure.

### CHECK OUT THE INTERVIEW

<http://www.radionz.co.nz/news/national/294914/%27i-just-try-to-be-as-normal-as-possible>.



## WORLD KIDNEY DAY 2016

This year the New Zealand Police were the targets of Kidney Health Checks, with staff from many of the renal units throughout the country paying a visit to their local Police station offering free blood pressure and urine checks.

The response was overwhelmingly positive with requests for more opportunities to be checked. Special thanks must go to the nurses and Drs who gave up their time to support the day and help raise awareness of the importance of getting your kidneys checked.

This year the New Zealand Police were the targets of Kidney Health Checks.

## HOKITIKA WILD FOODS / MARCH 2016



Held two days after World Kidney Day, we decided it would be fun to combine with local Cassie Lee, whose mother Robyn sadly died last year following several years battling kidney failure and was passionate about supporting anything that either helped people with kidney disease or to raise public awareness, who wanted to carry on where her mother left off.

So in typical West Coaster style Cassie gathered some of Robyn's friends and relations together and the "Wild Bush Kidney Clinic" was created. The Kidney Kebabs and Kidney bean, beef and bacon burritos proved popular and while the punters bought their food, I offered free kidney health checks to anyone passing by. To say I was overwhelmed with the response is an understatement, more than 250 Blood pressures taken 50 urines tested for protein and many conversations about kidney health and organ donation taking place. I was especially impressed with the numbers of young adults keen to know more about their kidney health.

To top off a great day the **Wild Bush Kidney Clinic** were named the **proud winners** of the **Best Overall Stall!**



## FROM THE CEO

Welcome to 2016 – a year in which, again, Kidney Health will be very much under the public spotlight.

As March rolls on, the Government's Health Select Committee is due to report back to Parliament on their consideration of National List MP Chris Bishop's Financial Assistance for Live Organ Donation Private Member's Bill.

Having attended both Select Committee meetings that heard oral submissions on the Bill late last year, it was already clear that there was general cross-party agreement that the current WINZ-based remuneration process was both woefully inadequate from a financial point of view, and cumbersome to the point that many potential donors didn't even bother engaging with the process. It is anticipated that the Select Committee will recommend an increase in the level of financial assistance available to live organ donors to at least the 80% provided for in the Bill, if not to the 100% of lost income and additional expenses incurred recommended by Kidney Health NZ in our own submission (and supported by a number of other submitters).

Alongside this, the Ministry of

Health is due to report back to Health Minister Dr Jonathan Coleman on their review of deceased organ donation and transplant services. It has been both a privilege and an enlightening experience to have been involved with the Expert Advisory Group supporting the Ministry in this review. Bound by a confidentiality agreement for the period of the review, I cannot of course go into much detail at this point. Suffice to say, however, that the review process has garnered a wealth of statistical information that has not previously seen the light of day, seen a range of clinicians and other health professionals from right across the country interviewed regarding their experience of the current regime for deceased organ donation, and identified a number of key barriers to deceased organ donation inherent in the current regime. The Ministry is due to report back to Dr Coleman with its findings and recommendations in the next month or so.

Kidney Health NZ (along with Kidney Health Australia) has been approached by the Australia & NZ Society of Nephrology, noting that patients travelling between Australia and New Zealand for holiday haemodialysis are now being charged in some public hospitals for their outpatient treatments. A similar concern was expressed to us by NZ's National Renal Advisory Board last year, highlighting in particular what appears to be a level of variation across NZ renal units in terms of the availability of 'away from home' dialysis for those on holiday or whose work commitments require dialysis outside of their home region. I recently had the opportunity to raise this matter with senior staff at the Ministry of Health, and also intend raising it with the various DHBs providing dialysis – offering Kidney Health NZ's support in undertaking a comprehensive review of 'away from home dialysis'. It is intended

that such a review would also undertake a stocktake of the various community-based options available (e.g. the Taupo holiday house managed by the Wellington Region Kidney Society, and the motor homes and caravan provided by local kidney support groups). While a more formal survey of dialysis patients will be undertaken as part of this review, if you want to share your experience of accessing 'away from home' dialysis with us in the meantime, please don't hesitate to email me ([max@kidneys.co.nz](mailto:max@kidneys.co.nz)).

Elsewhere in this newsletter, Carmel provides an update on the other major piece of work that Kidney Health NZ is currently involved in – the Ministry of Health's Chronic Kidney Disease (CKD) initiative, raising awareness of CKD in the General Practice setting. This nation-wide initiative has provided a timely reminder to us that, as important as our support for the more than 2,500 dialysis patients and 1,600 transplant recipients and their families is, there are another one in ten New Zealanders living with CKD – the vast majority of whom will be completely unaware of this. Yet the reality is, if the early stage kidney disease affecting those 300,000 individuals is not caught early enough – if it isn't addressed until more obvious symptoms appear, some 90% will inevitably progress to requiring dialysis or transplant. The potential this national initiative has to change the face of kidney health in NZ is enormous.

Thanks again for your ongoing support. And remember, we welcome your feedback, and any opportunity to visit your area with information and support, or simply to hear your stories.

All the best for 2016!

Max Reid,  
Chief Executive.



## ANITA'S STORY

Recently Anita received a kidney transplant, it was her fourth, I have asked Anita to share her story and she has very kindly agreed.

Anita is inspirational, not only because of what she has endured over the years but how she has dealt with it, she is one of the most positive people I have met, so here is Anita's story;

### **TELL US A LITTLE ABOUT YOURSELF.**

Born in Mosgiel in the late 60's. Family moved to Queenstown in the mid 70's and back to Mosgiel in the early 80's when ill health for both myself and my mum dictated that a home closer to a hospital was essential.

Skip a few decades ..... I am now 47 years old, married to Bryan and live in Outram, Otago with our King Charles Cavalier - Frosty. Up until around 2 years ago I worked full time as an Administration Manager, a position I have had for nearly 30 years. When my health deteriorated I chose to cut my hours so now I work 3 days a week and "on-call" as required. Since this last transplant I am more than able to go back full time but am just enjoying a bit of time to catch up with friends and family and enjoying life.

### **HOW OLD WERE YOU WHEN YOU WERE DIAGNOSED WITH KIDNEY FAILURE AND HOW DID IT IMPACT ON YOUR LIFE?**

I was 12 when first diagnosed back in 1981. The impact was huge on my life. I had no idea what my future was and in a way probably better that I wasn't too aware. At that time we lived in Queenstown but Mum and I had to live in Christchurch to learn dialysis and cope with all the side issues kidney failure has to offer.

The stress on the family was immense. My parents and brother were impacted severely. My father and brother used to commute at weekends to Christchurch from Queenstown when they were able. The family became a very disjointed unit for quite some time.

As the years went by I missed out on quite a bit of the socialising that a typical teenager would experience. Having no freedom was the hardest part. My fistula was never that great and therefore needling was always a battle.

There were no dialysis "holiday" houses /caravans or trips available back in the 80's so therefore no holidays for our family. The times I spent on dialysis were very difficult especially for my mother who was the primary carer.

### **YOU HAVE HAD FOUR KIDNEY TRANSPLANTS, CAN YOU TELL US A LITTLE BIT ABOUT THEM, (HOW OLD WERE YOU WHEN YOU RECEIVED YOUR FIRST ONE AND HOW LONG EACH ONE LASTED?) WERE THEY FROM DECEASED DONORS OR LIVING DONORS?**

First one at 12 (1981) – lasted a month. Second one at 15 (1983) – lasted 2 years. Third one at 19 (1987) lasted 28 years and now my fourth at 47 (2015) – to last forever. The first 3 were from deceased donors. Back in the 80's live donations were a huge ordeal and they also only took the organs from relatives. As medicine has progressed (thankfully) times have changed and while living organ donation is still a massive ordeal, medicine has improved this form of transplantation no end and now you can receive live donations from anybody. My fourth transplant on 29 June 2015 was from my brother. It was overwhelming the family and friends who came forth to donate me this next organ. My brother was the best match so he was chosen as the donor. A gift I can never repay.

### **HOW DID YOU MANAGE WITH THE TIMES YOU WERE ON DIALYSIS?**

Don't think "manage" is the word "survived" would be how I see it.

Dialysis was the pits. Life on dialysis, as far as I am concerned, is not life. I have been so fortunate to have had the last 28 years of freedom to travel, work, socialise and live. While I was only back on dialysis this last time for 8 weeks (until my brother was given clearance to donate), dialysis has

---

never changed – it still is a huge tie, a hassle and you feel crap.

I try not to let any opportunity pass me by as life is for living and I intend to take advantage of that. I see no point living in the past or trying to predict the future – whatever happens will happen and you can't change that. I feel lucky to be able to get out of bed every day and be well enough to enjoy each day. I walk up to an hour every day (every patient should have a dog) and try and keep healthy to the best of my ability. Being ill at a very young age probably has stood me in better stead to deal with the challenges I have been thrown along the way. I didn't really have a choice at 12 years old. I did what I was told and did what I had to to stay alive.

Transplantation was all I ever had my sight set on. I didn't see dialysis as a future. Everyone has different views on what their "quality of life" is but dialysis is not the quality of life I want. I am aware a lot of people cope with dialysis well and they are happy with that. I have great admiration for those patients who don't want a transplant and are happy to continue with dialysis to survive.

Generally, I didn't manage dialysis well at all and I saw it as the stepping stone to a better future.

### **WHAT WAS THE HARDEST PART ABOUT RECEIVING A KIDNEY TRANSPLANT?**

As far as the operation itself - there was nothing hard about this last one. The whole process was so smooth and with the advances in medicine/surgery etc it was nothing like the last 3. My brother and I were admitted on Sunday night. Transplant Monday morning. I was up out of bed on Tuesday as was my brother. He was discharged on the Thursday and I was discharged on the Saturday. *AMAZING.*

However, mentally – I think the hardest part for the first three transplants was knowing that somewhere in the country a family is in mourning as their close family member has passed away while I am ecstatic with a possible new chance of life in front of me.

My lucky 4th transplant was from my brother. This had its own impacts mentally. Here was my healthy brother, married and raising two children prepared to make this huge sacrifice and give me another chance at life. Emotions run very high at this time. As we all know, rejection is a hard fact of transplantation and in the back of my mind you just have this feeling "what if." However you need to stay positive and look forward and not back. My brother made a well informed decision to donate and if something unfortunate had occurred we would have had to deal with it.

### **WHAT WAS THE BEST PART ABOUT RECEIVING A KIDNEY TRANSPLANT?**

The feeling of wellness. I had taste buds. I had red fingers and toes with circulation. I had energy and felt 'alive'. And of course, freedom – no strict dialysis regime to hold you back. It is very difficult to explain the difference to someone who has never been lucky enough to receive a new kidney. Your whole life changes and you see everything so differently. It is like a blind has been lifted from a window and everything appears clearer.

I recall one of my specialists – and this is only recently – quoting that a transplant "is a form of treatment - it is not a cure". I had never thought of it like that before. For me it is a cure. I never looked at transplantation as he had quoted. Maybe because the majority of my life has revolved around "kidney issues, dialysis and transplantation"

I only see transplantation as the way forward.

### **HOW HAVE YOUR FAMILY AND FRIENDS SUPPORTED YOU THROUGH YOUR JOURNEY?**

It is indescribable the support I have had from family and friends. As soon as word got out that my kidney was failing I had numerous friends and family come forward to donate. Words can't describe how that made me feel. As my health slowly deteriorated I had housework done, gardens done, flowers, food, visits, car pooling – the list just goes on. . I am very humbled by all the support and feel so very lucky to have such wonderful family and friends around me. You need a good support structure in place for times when things appear rough. I know at times (dialysis times) I really couldn't be bothered answering the phone or having visitors – good friends realise and appreciate this. I was honest and told them how I felt and I then found they were happy to be there when needed and happy to give you that peace when you need some time out. You need to try not to cut people off all together because they are the glue that keep you going in the long run.

### **IS THERE ANYTHING YOU WOULD LIKE TO SEE HAPPEN TO IMPROVE THE CURRENT ORGAN DONOR RATE?**

Live donors need to be compensated. I could write a book about what my brother had to endure with WINZ to try and get a very minor piece of compensation while he took weeks off work to save my life. As this was my first live organ donation I did not appreciate the "red tape" these donors have to go through. Totally ridiculous when you see the difference they make and the money they save the country. I believe the donors should be fully

We get a good shot at a second chance (or fourth if you are lucky enough) with transplantation so make the most of every day.

compensated for loss of income, along with any support person that needs to take time off to help them in their recovery. I am sure our donor rate would improve if the country wasn't making it so difficult to do this fantastic life-saving procedure.

**THE FINAL WORD - IF YOU HAVE ANYTHING TO ADD.**

I can't express enough the difference my brother has made to my life. I have been extremely fortunate to be able to receive four transplants and with the fantastic expert care

from our knowledgeable medical profession I now see a future AGAIN.

There is one thing that we must always remember. We get a good shot at a second chance (or fourth if you are lucky enough) with transplantation so make the most of every day. However - don't be blasé. Take your drugs, take care of yourself and do what you are advised to do from the experts. You have to try and make the most of a difficult situation that is essentially out of your control - so grab it with both hands and ENJOY it.

You have to try and make the most of a difficult situation that is essentially out of your control ...so grab it with both hands and ENJOY it!

## NATIONAL RENAL ADVISORY BOARD



Kidney Health was pleased to recommend Mardi Thompson as the Consumer Representative on the Ministry of Health's National Renal Advisory Board, replacing Michael Papesch who has held that position on the Board for the past six years.

Mardi, a kidney transplant recipient, moved to the Hawkes Bay from Australia three years ago. Back in Australia, Mardi served as a consumer representative on both the Kidney Health Australia board and the National Health and Medical Research Council. Originally training as a Nurse, Mardi has subsequently completed a Master's Degree in Management, and currently works as a recruitment consultant. Her appointment was enthusiastically endorsed by the NRAB. Our heartfelt thanks to Michael Papesch for his staunch representation of consumer interests and

concerns on the NRAB, and for his continuing involvement, independent of the NRAB, as a Kidney Health NZ board member. new tools available to primary care to help manage patients in the community at an early stage of their disease has the potential to transform thousands of lives here in New Zealand.

## KIDNEY TRANSPLANTATION SOME ENCOURAGING NEWS

More Kiwis were given an organ transplant in 2015 than in any other year, according to the Auckland District Health board.

The combination of deceased and live donors meant 232 people were given an organ transplant, an 8 percent rise from 214 in 2014.

Fifty-three deceased organ donors donated heart, lungs, liver, kidney or pancreas to 158 transplant recipients, a 14 percent increase from the 138 recipients in 2014.

Seventy-eight live donors donated a kidney or part of the liver to 78 recipients.

The Organ Donation New Zealand (ODNZ) has been given an additional \$500,000 allocation per annum, which began four years ago.

“ODNZ believes that the increase in deceased organ donors has resulted from the quality program which the additional funding had supported, with the support and commitment of intensive care nurses and doctors throughout the country,”

says ODNZ clinical director Dr Stephen Streat.

### READ MORE

<http://www.newshub.co.nz/nznews/organ-donation-at-its-highest-in-2015-2016010711#ixzz41hHGkk2B>

## RENAL VIT™

Introducing the first and only fully funded multivitamin and mineral supplement developed in New Zealand specifically for people with chronic kidney disease.



### WHY DO PEOPLE WITH KIDNEY PROBLEMS NEED RENAL VIT™?

Kidney disease changes the way many vitamins and minerals work in the body. The dietary restrictions, medications and dialysis that are used to manage kidney disease means patients are more at risk of being deficient in certain vitamins and minerals.

### WHAT IS IN RENAL VIT™?

A unique combination of both necessary and beneficial nutrients at the right dose for people with chronic kidney disease.

It doesn't have certain vitamins and minerals that is the wrong dose may be harmful to people with chronic kidney disease.

### DOSAGE

One capsule a day provides the essential vitamins and minerals needed by people with renal problems.

### WHERE CAN YOU GET RENAL VIT™?

It is fully funded on Special Authority for people with Chronic Kidney Disease or on dialysis. It is also available from pharmacies for all stages of chronic kidney disease – a charge will apply.

Talk to your doctor to see if Renal Vit™ is for you.

---

## SUPPORTING KIDNEY HEALTH NEW ZEALAND

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, 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/20609680609157>