Kidney Health
NEW ZEALAND

Prevention • Support • Research

WINTER 2015

IN THIS ISSUE

- KHNZ update
- From our Medical Advisor
- Transplant Bonds Brothers
- Renal Cookbook available now
- Nelson support
- Live organ donor bill drawn from ballot
- From our CEO

> "And what a winter it has been so far, with record low temperatures being recorded around the country. It certainly makes getting up in the morning a little harder."

Sandy Neale, Pre dialysis educator at Christchurch Renal unit, presenting on their Facebook page for renal patients

We have had a very busy few months with kidney health information forums being held in Palmerston North and a Chronic Kidney Disease workshop for Practice Nurses and GPs, having a stand and attending the New Zealand Society for the Study of Diabetes (NZSSD) in Wellington and the Primary Care Symposium also in Wellington, and attending the annual Renal Society of Australasia conference held in Perth.

The NZSSD symposium discussed some worrying statistics being shared, Dr Jeremy Krebs told how there are 50 new patients diagnosed with diabetes a day, with an increase in the prevalence of younger people being diagnosed, increase in the complexity of the disease and increasing disparity.

One of the speakers at the Primary Care Symposium Buck Shelford, former All Black captain spoke about his health issues and how this has influenced his work with other young rugby players, trying to instil the importance of looking after your body with good nutrition and exercise. It was great to hear about the many positive health initiatives that are in being put into place around the country in the primary care area.

Jacqui Thompson, Clinical manager Manawatu Horowhenua Tararua (MHT) Diabetes Trust speaks at the KHNZ forum in Palmerston North

THE RENAL SOCIETY OF AUSTRALASIA 2015 – PERTH

The RSA in Perth was a wonderful opportunity to keep up to date with the advances and practices in kidney disease. One of the keynote speakers Prof Anita Molzahn talked about her research exploring the experiences of people with kidney disease; this was done by encouraging people to tell their own personal stories. The participants were interviewed and these were recorded, these were then collated either in an audio-visual format or in photographs with voice overs. These were then turned into an art exhibition at places like libraries, conferences and the Ministry of health offices. The aim was to enhance the understanding of kidney disease and its impact on people.

Dr Brian Silva talked about dialysis in the elderly; he told how evidence for survival shows dialysis survival is much worse in the elderly. Although age itself is not a predictor of who will do well on dialysis. It's not about SURVIVAL but Quality of Life!

Sandy Neale from Christchurch Renal Unit represented the Kiwis and did us proud, talking about the initiative she and her colleague Becky Hayston had developed to enable patients on dialysis to connect through Social Media. The Facebook page is a closed group, therefore comments are private to the group, and requests are made to join the group with the decision to accept these are made by the administrator of the page. It is exclusively for patients and their supporters. Membership has grown quickly and there has been a weekly coffee group formed as a result. For those of you interested in joining the group check out their Facebook page Kidney Failure Uncensored.

In another interesting session Samantha Harrington talked about supportive care for aboriginal patients in the Northern Territory. With 70% of patients required to relocate to Darwin to commence dialysis treatment, low incomes make regular visits home very difficult, relocating combined with long distance from family and friends, and cost of accommodation lead to poor outcomes. To overcome these issues a working relationship was developed between the Northern Territory Renal Services and Territory palliative care. Video communication has been established linking patients and their families, as well as providing an improved level of understanding about supportive care. The result has enabled long term renal patients to return home to their community for end of life care, which is funded by the Government.

Monitoring Home Haemodialysis patients via a smartphone app was a very interesting talk given by Mary Ann Nicado from New South Wales. In her unit there had been a 24% growth in patients dialysing at home. Home visits were resource dependent and many of their patients lived some distance from the hospital, so an app was developed that patients downloaded onto their smart phone and enter their details. Over time it downloads their treatment sessions with weight or high blood pressure readings alerts that occur when loaded. Tis information is loaded into the cloud so the nurses are able to review the patients' status. Patients are also able to indicate on the app if they are happy or sad – nurses use this information to decide who they need to contact first. Trends are shown making it easy to monitor the patients. The feedback from the patients included; the app was easy to use and they felt more relaxed now they know their treatment is being monitored.

FROM OUR MEDICAL ADVISOR – DR COLIN HUTCHISON

Colin is the Kidney doctor (Nephrologist) for Hawke's Bay. He moved to the Bay in 2012 from Birmingham in the U.K.

Colin is married with 3 school age children. After the initial shock of the Hawke's Bay's sunny climate his family has settled in quickly and are greatly enjoying life in New Zealand.

Colin has been excited to become increasing involved with Kidney Health New Zealand since arriving in New Zealand because of his passion for advocating on behalf of patients. Colin is a great believer that if we focus on "doing the simple things well" a whole lot of patients will have a better quality of life than they do now.

Colin has had an academic career in the UK, leading a research team exploring the treatment of kidney failure from the cancer Multiple Myeloma. This background has given him insight into the importance of high quality timely research.

Before moving to New Zealand, Colin was well aware of New Zealand's heritage as a world leader in home dialysis options. He sees that this will always be an area of strength in the New Zealand renal community but he is acutely aware that going forward our renal teams will have greater and greater challenges ahead to keep managing patients at home. This challenge will largely come because people are starting dialysis with more health complaints than in previous years.

Colin is very keen that over the next few years Kidney Health New Zealand works with GPs and community teams to empower them to provide early high quality care aimed at diagnosing and managing patients' kidney complaints early before severe kidney failure occurs.

Dave Joy, left, and Paul Laing from the Singlespeed Society, Rotorua Mountain Bike club's Gregg Brown, Regan Johnson from Kidney Health NZ and kidney donor Lance Tavinor Photo/Ben Fraser

TRANSPLANT BONDS BROTHERS

An update on the story in our last newsletter, Lance Tavinor talks about his experience as a live kidney donor to his brother.

He is one kidney lighter but just as sharp as ever.

Today Lance Tavinor returns to work at Cyclezone after giving the ultimate gift - one of his own kidneys to his sick brother Grant.

Mr Tavinor, 39, bears four scars of the two and a half hour surgery in May. But it was all worth it, he said. "He's got some normality back into his life," he said of his brother Grant. "He's got a lot more freedom. That day to day routine of having to do dialysis - that's gone. He's back to work part-time this week. This has definitely brought us closer together."

On May 18 at Christchurch Hospital, his left kidney was removed and hours later it was transplanted into his brother.

It was a straightforward operation, he said, with no side effects other than a bit of discomfort for the next two weeks.

"It's been pretty awesome the last six weeks. The first couple of weeks were pretty rough.

It's quite invasive and they moved a few things around because of how the kidneys are connected to your internal plumbing. You feel sore in more than one area but I'm getting used to functioning with one kidney. It's all good.

The outcome for the person who benefits is what you should think of. I wasn't a donor at all before; it's not something I'd really thought about."

The pair could not recover together; they were in different wards a floor apart. "I went to visit Grant a couple of days later as he was more isolated. I got locked out of my ward in just my gown."

On average, people only live for four to five years after they start dialysis, although some people can live for much longer.

Before his surgery Mr Tavinor had raised money for Kidney Health New Zealand through mountain biking events.

Yesterday the Rotorua Singlespeed Society handed over $6000 to the charity following on from the Anzac Singlespeed Championship in April.

"It's absolutely brilliant," said Kidney Health New Zealand ambassador Regan Johnson, who received a kidney three months ago.

"We appreciate this enormous effort. Having a transplant is life changing. You feel nearer to 100 per cent than death warmed up."

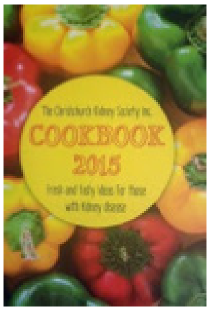
Thank you so much Lance and your support team for your support for our work.

THE FACTS

For the person receiving the kidney the advantages of a living donor transplant are:

- Having a transplant before the need for dialysis
- A shorter time on dialysis (this is especially important for children)
- The operation can be planned for a time that suits the potential donor
- A better success rate - the transplanted kidney usually works straight away and lasts longer
- A longer life expectancy than when living on dialysis

A NEW COOKBOOK FOR PEOPLE WITH KIDNEY DISEASE



Introducing the latest recipe book for kidney patients. This has been produced by the Christchurch Kidney Society.

It is hoped that within this collection of recipes you will find some that fit your dietary requirements and tickle your taste-buds too. This book also includes some general pointers to help you with your choices from the renal dietician at Christchurch Hospital, and it has the Potassium and Phosphate content of each recipe.

The cost is $15:00 including postage

If you would like to order a book you can contact us on 0800 543639 or email info@kidneys.co.nz or the Christchurch Kidney Society at c.ks@xtra.co.nz

CONSUMER COUNCIL MEETING NOTICE

When Kidney Health NZ offered to fund a gathering of kidney health 'consumers' – donors, recipients, those on dialysis or the waiting list for transplant – in late 2013, the response was more than we could have hoped for. More than twenty consumers met in Wellington the following February for what envisaged to be a regular, if infrequent, Consumer Council gathering.

For various reasons, there hasn't been an opportunity to convene a further Consumer Council meeting since then. Various factors – including changes in the Kidney Health NZ board membership and to the structure and make-up of the Kidney Health NZ staff team –delayed such a meeting. That is, until now.

Kidney Health NZ is pleased to announce a second Consumer Council meeting, to be held in Wellington on Saturday, 19th September, between 10.00 am – 2.30 pm.
We are committed to ensuring that, as the organisation charged with advocating for Kidney Health consumers and their families, our advocacy is clearly informed and influenced by the voice of those we seek to represent.

The programme for the day will include a review of progress since the last meeting an update on current priorities for Kidney Health NZ's annual work programme discussion as to the best way forward for the Consumer Council – when, and how best to meet; how often; with what purpose discussion as to how Kidney Health NZ can better relate to and support local kidney societies and support groups the opportunity for you to raise any other concerns and issues.

For further information, please phone Carmel on 800 KIDNEY (543 629).

SUPPORT IN THE NELSON AREA FOR PEOPLE WITH KIDNEY DISEASE AND THEIR FAMILIES.

Linda Richards has come on board as the local support person for those people in the Nelson/Marlborough region, she is keen to hear from those people affected by kidney disease in the region who might just feel like a chat or get together over a coffee.

You can contact Linda on 03 548 2748.

MEMBER'S BILL WILL BOOST FINANCIAL SUPPORT FOR ORGAN DONORS

› article from scoop.co.nz

Chris Bishop, National List MP based in the Hutt Valley, is delighted the Financial Assistance For Live Organ Donors Bill, a Member's Bill in his name, has been drawn from the ballot and will be debated by Parliament.

The purpose of the Bill is to increase the financial assistance provided to people who, for altruistic reasons, donate kidney or liver tissue for transplantation purposes.

The Bill will increase the support for donors from the equivalent of the sickness benefit to the equivalent of 80 per cent of the donor's pre-operation earnings – the same formula applied to income support for ACC recipients. The Bill also provides for the payment of childcare assistance for those who require it during their convalescence.

"I was inspired to pick up this Member's Bill, which was originally put forward by Hon Michael Woodhouse, after talking to Sharon van der Gulik at one of my first meetings as a candidate in the election last year," Mr Bishop says. "She had been living with renal failure for more than two years and needed 15 hours of dialysis a week – before her son donated one of his kidneys to her.

"At the public meeting, Mrs van der Gulik spoke of the financial hardship that her son faced in the six weeks he spent recovering from the procedure. She argued he deserved more. I agree.

"If this Bill passes into law, greater support will be available to people like Mrs van der Gulik's son.

"Organ donation rates in New Zealand are improving, but are still too low. It's important they increase - live kidney donation is the least expensive form of treatment for end-stage renal failure, and significantly improves life expectancy.

"This Bill is a small but important and helpful step to increasing the number of people who donate organs.

"Wider work to increase the number of donors is being led by the Minister of Health. Budget 2014 allocated $4 million over four years to set up a National Renal Transplant Service to increase the number of live kidney donor transplantations. The funding covers donor liaison co-ordinators and continuation of the New Zealand Kidney Exchange programme. Last year's funding increase builds on the $4 million invested in Budget 2012 to raise awareness and encourage more people to donate organs," says Mr Bishop.

Kidney Health New Zealand is excited this bill has been drawn particularly as part of it's Manifesto focuses on this issue as below;

Reimbursement of live donors' expenses

› from KHNZ Manifesto 2014

What is the issue?
Some otherwise willing live donors delay or decline to donate due to potential loss of income, during the four to six weeks recovery following surgery. Recent research from Victoria University indicates that patients are reluctant to ask potential live donors because of the financial impact that being a donor would have on family finances.

The World Health Organisation's Guiding Principles on Organ Transplantation and The Declaration of Istanbul on Organ Trafficking and Transplant Tourism, for example, both confirm that reimbursement of lost income and medical expenses for donors is acceptable.

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 subsistence and medical expenses incurred post-discharge.

The Private Member's Financial Assistance for Live Organ Donors Bill, proposes increased compensation to live organ donors, in line with ACC payments, to cover 80% of live donor lost income. This Private Member's Bill was not drawn from the ballot in this term of Parliament.

Kidney Health New Zealand supports an increase in the level of compensation of costs to live donors.

Why is it a problem?
The current reimbursement for potential live kidney donors does not cover the actual costs of donation for many. Uptake of the existing programme has been low and transplant units still report that some people are deterred from considering live donation because of the loss of income involved, while others who do go ahead suffer financial hardship as a result of donation.

The WINZ administered Sickness Benefit programme does not cover the costs of live donors, is not customer friendly and WINZ staff are often unaware of its provisions.

Recommended Actions
There is an existing appropriation in the Ministry of Social Development for the current Sickness Benefit programme which has been consistently underspent (only $32,670 was spent in 2010; no updated information could be found in the 2014/15 Estimates) and this could be used to fund an increase in the level of compensation to those donors who would be out of pocket otherwise.

- **KHNZ recommends that:**
A programme be developed by the Ministry of Health to fully reimburse the costs (including loss of income) for live kidney donors based on the Financial Assistance for Live Organ Donors Bill.
- The Ministry of Health be directed to advise further on options for developing such a programme, including whether legislative change is needed or whether it could be introduced under the current Human Tissue Act (2008).
- The programme be developed as a health initiative, administered by the Ministry of Health, rather than as a welfare programme administered by WINZ
- Re-imbursement be set at 100% of costs and lost income, and
- The costs of the new programme are met by transferring the annual funding from the Ministry of Social Development to the Ministry of Health.

Estimated cost
This programme would spend currently appropriated funding from the Ministry of Social Development budget. No new net fiscal cost expected.

COMMENT FROM KHNZ CEO REGARDING ORGAN DONATION FOLLOWING RECENT PUBLICITY ON THE SUBJECT.

It is always encouraging to read articles that keep New Zealand's low rate of deceased organ donation in the public mind (NZ Herald, 17 July). It is true that, despite a positive spike in the donation rate last year – and significant financial investment from the health budget over a number of years – NZ continues to have one of the lowest rates of deceased organ donation in the world. That other countries such as Australia – or, closer to NZ in population, Croatia – have each achieved significant growth in their rates of deceased organ donation clearly demonstrates that NZ can and should do better.

A recent report from the Ministry of Health's National Ethics Advisory Committee highlights the growing dilemma NZ faces unless kidney donation rates in particular – from both live and deceased donors – increase dramatically. With over 600 patients of the kidney transplant list, an additional 170 added to that list each year, but only on average around 110 kidney transplant operations performed each year the gap, the NEAC report rightly notes, will only get worse.

The solution, however, is not as simple as your article suggests. While Australia lifted its deceased organ donation rate from around 10% to 17% over the 2009-2013 period (during which time NZ's rate actually declined), the Australian Organ Transplant Authority readily acknowledges that this massive improvement was the result of a broad range of initiatives, rather than being attributable to any one single factor. Interestingly, those initiatives did not include moving from a so-called 'opt in' donor database to an 'opt out' model as proposed in your article. Likewise, various reviews of Spain's world-leading rate of deceased organ donation clearly indicate that there is no single intervention that can be identified as most important.

While NZ must heed such caution, we cannot however be complacent. That there may not be one single solution, does not mean that we should not implement – as have other counties with proven success – a range of initiatives. All the evidence suggests that these must include encouraging families to openly discuss their wishes regarding organ donation, and training Intensive Care staff to initiate and facilitate conversations with family members when it becomes clear that organ donation may be an option. The Associate Health Minister Peter Dunne's recent call for a review of legislation regarding deceased organ donation – in particular the right of family members to overrule an individual's clearly expressed intent to be an organ donor – is also a step in the right direction.

But the most effective changes remain with you and I. Deciding to donate our organs – either during our life (in the case of our kidneys and liver tissue), or upon our death – and above all discussing that choice with those closest to us, so that they know, understand and respect the life-giving decision we have made.

FROM OUR CEO

As Carmel has kindly reminded us – as if we needed reminding – it's the middle of Winter. The trees are bare, there's been snow on the ground, getting out of bed in the morning is that little bit more challenging. It's usually the time of year when things life tends to flow at a slightly slower pace. Not so for Kidney Health NZ.

As the various articles in this Winter newsletter suggest, there's a lot happening around kidney health at the moment. The drawing of Chris Bishop's Private Member's Bill from the ballot provides a real opportunity for you to have your say around the need to increase support for live organ donors. While it is unlikely that the Bill will be read in the House for a few months – there's currently quite a backlog of Bills – it will inevitably go to a Select Committee, at which point there will be a public call for submissions on the Bill. If you need any encouragement to support the Bill, read the recent Dominion Post article on Elsie Howarth's experience as a live kidney donor, which is now posted on our website. Never made a submission before? Find out how at http://www.parliament.nz/en-nz/about-parliament/get-involved/submission/00CLOOCHvYrSaySubmission1/how-to-make-a-submission. We'll keep you informed of the Bill's progress on our website.

Various other activities we've been involved in are reported on elsewhere in this newsletter. "But, wait" as they say, "there's more!"

Kidney Health NZ is also actively involved in a new Ministry of Health initiative to draw far greater attention to chronic kidney disease (CKD) at primary health (General Practice) level. The Ministry's CKD Consensus Statement project aims to provide a range of resources to both GPs and Practice Nurses to enable them to identify as early as possible patients with (or at risk of developing) CKD. Of the estimated 400,000 New Zealanders with or at risk of CKD, it is likely that only half have actually been diagnosed as such. The opportunities for early identification and intervention are huge – and this Ministry initiative represents a real opportunity to make a difference in thousands of New Zealanders' lives. Kidney Health NZ's role in the project will be to support the training of Primary Healthcare Nurses. We have been granted permission to adapt an internationally recognised Australian training resource for the NZ context, and will then be responsible for the coordination and facilitation of the training rollout.

Also on our 'to do list' is supporting the Ministry's review of organ donation in NZ. Following the release of a report from the Ministry's National Ethics Advisory Committee, further criticising NZ's low rate of organ donation – particularly deceased organ donation – the Associate Health Minister Peter Dunne has called for this review by the Ministry. While the terms of reference for the review are still being developed, Kidney Health NZ's support and input has been welcomed by the Ministry.

So, some busy times ahead! But not so busy that we wouldn't welcome any opportunity to pay your local support group or kidney society a visit. As I mentioned in the last newsletter, I'm keen to get around the country and to meet with as many groups as I can. Kidney Health NZ exists to support you and to advocate for your hopes and concerns. The best way for us to do that is to hear those concerns from you face-to-face. Please do phone or write to me or email if you'd like me to visit.

Warm regards from the wintry South.

Max.

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