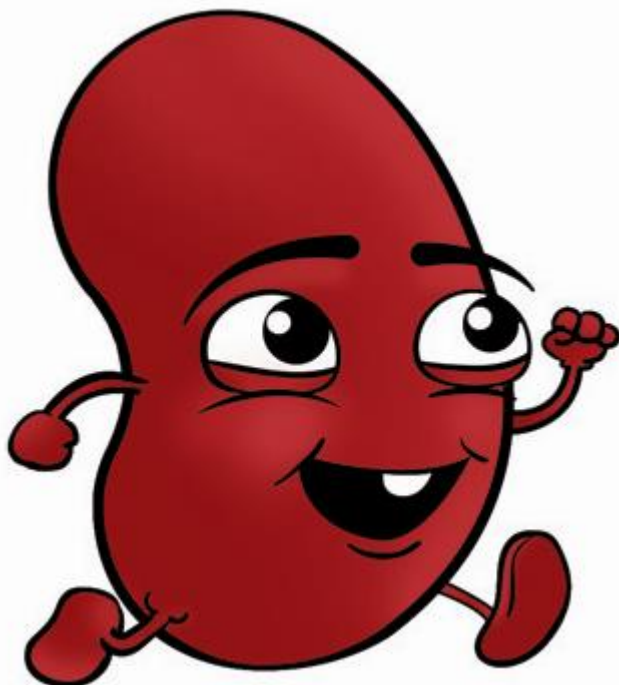


OTAGO KIDNEY SOCIETY INC



Contact Details for your Committee are outlined below. Please do not hesitate to contact any of them if you would like some support or information. If we can help we will, if not we will endeavour to point you in the right direction.

Shane Boyle : Contacts: 027-4896265. Email: Shane@oks.nz

Joan Von Metzinger : Contacts: 021-0561831. Email: Joan@oks.nz

Natalie Brown : Contacts: 027-4543512. Email: Natalie@oks.nz

Glen McLennan : Contacts: 454-3556, 021-806575. Email: Glen@oks.nz

Maree McDonald : Contacts: 03-4667135, 02-23932165. Email: Maree@oks.nz

Anita Lloyd : Contacts: 03-4862268, 027-4898843. Email : Anita@oks.nz

Liz Edwards : Contacts: 03-4554401; 021-0476187. Email: Liz@oks.nz

Cath Swale : Contacts: 027-2935056. Email: Cath@oks.nz

Fiona Ferguson : Contact: Fiona@oks.nz

*We love hearing your stories, so any articles of
you think may be of interest,*

please forward to

PO Box 3, Mosgiel 9053 or email direct to us at
newsletter@oks.nz

Please note if you wish to send an email to the
entire committee you can send it to
oks.committee@oks.nz

From the Chairman's Desk

Winter is certainly here as this week's icy blast has confirmed. We hope you're all keeping warm and dry.

There's been a change of roles and responsibilities within the OKS committee. Our evergreen and energetic Anita Lloyd has taken an important and relatively recent new role of managing patient visits in the dialysis unit. We've found that this is a positive way that we can connect with our kidney family in Otago-Southland. Anita also now puts together the newsletter which is great for many reasons including making it happen! We're also pleased to advise that Joan von Metzinger, our Kidney Kids representative on the committee, has taken over secretarial duties from Anita. Joan brings some fresh and new ideas for promoting kidney health in our region and we are enthusiastically looking forward to implementing some of her initiatives. We'll keep you posted on our plans in our newsletters.

Last week we were very sorry to hear of the passing of Maryanne McIlhatton. Maryanne and John really helped Otago Kidney Society with getting patients together in Central Otago hosting several lunches at their home. A couple of years ago I had the pleasure of meeting Maryanne and John at an OKS lunch in Cromwell. I was immediately impressed by Maryanne's positive attitude and pragmatic approach to life on haemodialysis as well as John's committed support to her care. John and Maryanne also had a great system between them that allowed John to work full-time and still be the principle carer around her home haemodialysis. Personally, I consider them to be role models for other couples and families dealing with kidney disease and home dialysis treatment. Our condolences and kind thoughts go out to John and the McIlhatton family at this sad time.

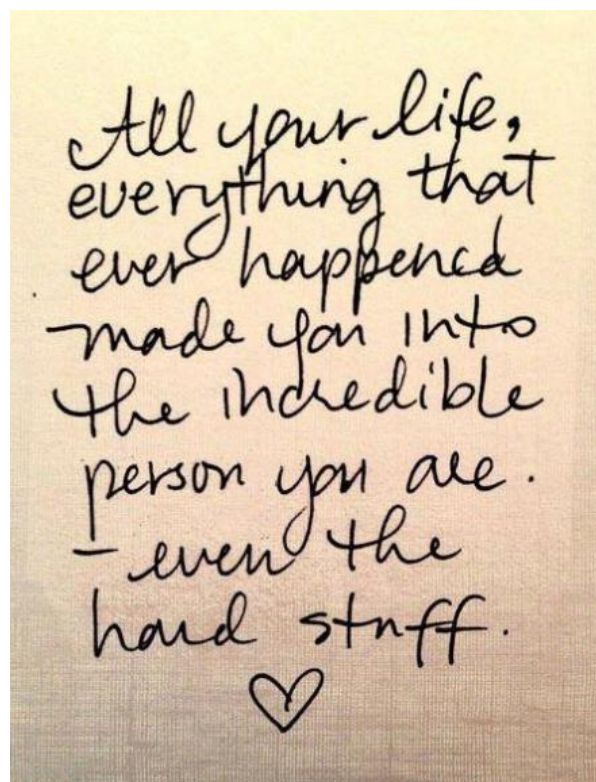
I really enjoyed attending the last OKS lunch at the China Palace, renewing friendships and meeting new ones. Very much looking forward to our next get-together.

Kind wish and stay warm

Shane Boyle
OKS Chairman

Patient Visits

For those of you in the unit, you may have seen that the Otago Kidney Society is now doing monthly visits. These are the second Monday of every month. We realise as nephrology patients you would rather keep your distance from the Unit and given the good response we are getting to the unit visits, we are looking at trialling "home visits". So if you are a patient/support person at home and would like a chat please contact Anita (details on front page) and a suitable time/date can be sorted.

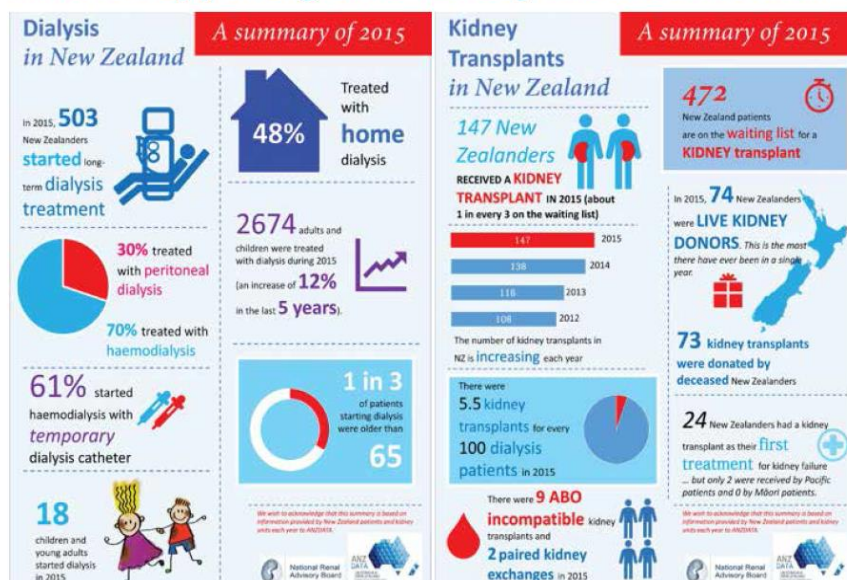


World Transplant Games

The Transplant Games are well underway in Spain with more than 2200 athletes competing from 54 countries. New Zealand is represented by 12 athletes and as at the time of putting this newsletter together the medal tally was at 7. Awesome.



What's happening with Kidney Diseases in New Zealand



This summary is based on information received by ANZDATA from renal units in NZ

Travelling on Peritoneal Dialysis (PD)

As narrated to Natalie Brown

I had the pleasure of visiting the home of Lynn and Kevin Keogh where they shared their experiences with me of travelling while being on PD.

The Keogh's have travelled with Lynn on both manual and APD.



The one thread that came through the meeting was the part that Baxter played in their travels and how fantastic they were in helping them with their travels from start to finish.

The main reason for writing this article is because the Keogh's were keen to share their experiences and learnings and to pass this onto other patients on PD who want to travel.

Both the Keogh's children live in Australia, one in Perth and the other in Melbourne. It was their grandson's first birthday in Perth that was the reason for their latest trip.

One thing that added to the complexities of their trip was the fact that Lynn is blind and therefore is dependent on Kevin for helping Lynn go on and off the machine every night. Lynn has a guide dog but it was too hard to take him with them as he would have had to have an import and export licence and have blood tests before he was allowed back into NZ.

One of the first things to organise was to get a case from Baxter for their machine so they could protect the machine while travelling.

If you are travelling to anywhere in Australia or New Zealand you will need to give Baxter a month's notice so they can arrange to have the products sent ahead for you. If you are travelling further afield Baxter need 3 months' notice. Please consult your unit and Baxters prior to booking.

Western Australia use a different product than Baxter so this added more challenges. But again Baxter came to the rescue and arranged to have the equipment trucked from Melbourne to Perth.

Thus ensuring all products were in Perth when the Keoghs arrived.

Plane Trip



There are a number of hoops to jump through before you get off the ground. Of course there are extra forms to be filled out. Firstly there are medical forms from the hospital, where the Dialysis Unit were extremely helpful.

The travel agent also had forms for filling out, the Keoghs used a travel agent which made this process easier.

Then there are the forms required by airlines where their doctors determine if they will fly you. On their travels the Keoghs used both Air NZ and Jetstar.

This can be a bit of a process because you need your hotels booked a month in advance so often this means having your bookings made before you know you can fly.



The machine weighs 17 kilos and is free to take on board the aircraft. But of course this means an extra piece of luggage to take with you and you hope that the staff at the airports will take care of your precious cargo for you. Although Kevin did say that every time they went to get the case with the machine in it off the carousel it was upside down, even though it had numerous stickers on it. Luckily for them this did not cause any problems for the machine.

Of course for the Keoghs with Lynn unable to see it meant Kevin had to get a trolley for the 3 cases. The ground staff were very helpful and even arranged wheel chairs for Lynn, but of course this made things logistically impossible for Kevin, so Lynn walked alongside the trolley.

The machine has 2 Lithium so special permission was also required to be able to take the machine on board. Baxter's arranged a letter to say the machine with the batteries were okay to fly.

A concern the Keoghs had was what if there was a flight delay and they could not get their luggage for some reason what effect would this have on Lynn if she missed dialysing.

The Machine

Because Baxter is not the supplier in Western Australia if the machine had broken down while they were in Perth, the Keoghs would have had to travel back to Melbourne to get it fixed.

Baxter supplied manual bags in the case of emergency or the machine breaking down, another good travel tip to keep in mind.

Overseas support

Australia and New Zealand have a reciprocal health agreement so if anything goes wrong you can go to a public hospital with your passport and get help. The NZ government picks up the price tag for this.

Baxter provide 3 0800 numbers in the case of emergency and the machine breaks down or you need help with anything else.

Baxter provided a physical address of a Dialysis Unit in Melbourne in the case of emergency

Drain Bags, cassettes, mini caps, supplies etc

Because the Keoghs were not away for a full month the supplies could not be split so after visiting Perth the Keoghs had to take the equipment left after their West Australian visit back to Melbourne for their stay there. This meant they had to make sure they had 2 suitcases with enough empty space so they could fit these extra supplies into their luggage on their way back to Melbourne. This also meant that the bags for the extra days had to be left behind in Perth and ended up having to be disposed of.

Because the Keoghs were travelling to Margaret River in Western Australia for their holiday they had to take the supplies that were delivered to Perth with them to their destination. If someone had been at the Margaret River accommodation then the supplies could have been delivered there.

This meant they had to hire a large vehicle to fit 3 suitcases, 3 adults and supplies for their trip to Margaret River.



The Keogh's had a wonderful trip and were busy everyday seeing the sights and enjoying the family.

Kevin and Lynn are regulars at our lunches so come and have a chat with them they would love to share their story with you and help in way they can.

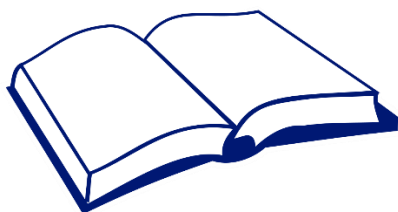
Our thanks to them for sharing their story with us.

Lynn celebrating her grandson's first birthday – best excuse for a holiday....



Entertainment Books

The 2017/2018 Entertainment Books are available for sale now. They are \$60.00 each and a percentage of sales goes to our Society. These books are full of great savings and easy to get the return on your money. You can purchase these off anyone on the OKS Committee or email us at oks.nz@live.com. There is also the digital version available which you can purchase at www.entbook.co.nz/260017s



News from the Unit

It has continued to be a steady time in the dialysis unit with a number of patients recently completing their home haemodialysis training and heading away to commence home dialysis. We are as always extremely grateful to the OKS for the support we receive and for the visits to patients that have commenced again. These are very worthwhile and much appreciated by those who are commencing their training.

Recently almost all the staff completed training on a new Automated Peritoneal Dialysis Cyclor *Claria*. This is a cyclor that uses a data connection over the cellular network, for which the DHB has agreed to pay for. As a result of using this technology all of the dialysis prescription can be done remotely and sent to the patients dialysis machine from the unit without the need for the patient to come to the unit with their cyclor, or for the nurse to call them and talk them through it over the phone or for using the pro-card memory cards. Not only this all of the treatment data re the dialysis and alarm problems can be viewed on clinic by the Doctor or in the dialysis unit by the dialysis nurse and management decisions can be informed from this data.

The data is stored on a computer server, referred to as Sharesource, and is accessed via the internet on a secure site that meets industry, NZ Ministry of Health and DHB IT teams requirements. This system is used widely in Australia, US, UK and Europe.

If there is anything the staff in the dialysis unit can do to help in regards to dialysis matters please don't hesitate to call the unit Monday-Friday 8:30am – 4:30pm.

All the very best to you all.

Blair Donkin on behalf of the dialysis unit staff.

As I get older I realize:

1. I talk to myself, because sometimes I need expert advice.
2. Sometimes I roll my eyes outloud.
3. I don't need anger management, I need people to stop pissing me off.
4. My people skills are just fine. It's my tolerance of idiots that needs work.
5. The biggest lie I tell myself is, "I don't need to write that down, I'll remember it."
6. When I was a child I thought naptime was punishment. Now it's like a mini-vacation.
7. The day the world runs out of wine is just too terrible to think about.
8. Even duct tape can't fix stupid, but it can muffle the sound.
9. Wouldn't it be great if we could put ourselves in the dryer for 10 minutes; come out wrinkle-free and three sizes smaller?
10. "Getting Lucky" means walking into a room and remembering why I'm there.

A Report from the Southland Kidney Society (Invercargill)

The Southland Kidney Society is a small group that meets Bi-monthly in the Community Trust Rooms in Invercargill. We are very fortunate to meet in a cosy warm environment on these winter evenings especially and I feel this helps for a good member attendance at our meetings. We always attend to meeting agenda first and follow each meeting with supper which allows a chat time for the members to fraternize with each other. Over the last year we have had a few new faces around our table and we always welcome them and encourage their support with and to each other in the group. Our meetings are very relaxed.

Early this year we had a lengthy discussion to purchase a chair for the Dialysis Unit in Dunedin, and after discussing this with Blair Donkin in the unit a chair was duly ordered from Tekmed and has since been delivered to the Dialysis Unit in May. (A grey and red chair for a Southland look!) May the team in the unit enjoy many years of treating patients on this chair and also may it assist in making the job easier for them too!

On April 8th we held a Kidney Health Forum at the Invercargill Workingmen's Club. We engaged Max Reid & Carmel Gregan-Ford from Kidney Health NZ, Simon Donlevy from the Southland Hospital Pharmacy who spoke on Medications, Anita Lloyd from Dunedin who spoke on her journey of receiving 4 Transplants, and lastly Jonathan and Marie Muhl who tragically lost their son in January of this year and they gave combined in delivering us a very interesting talk on their journey of making the decision to donate his organs for transplant.

Both Max and Carmel spoke at length on their work with Kidney Health NZ and they certainly represent their passion for this work in all that they do throughout the length and breadth of NZ. Carmel had spoken at a previous Forum in Invercargill about 7 years ago and her work with Education in this field has inspired many. A very enthusiastic and vibrant speaker! Simon delivered a very in depth coverage on Medications etc and many of those present remarked on what they learnt from his knowledge and information with his power point presentation, on the drugs that one has to take both pre and post transplant. The power point views certainly deliver the message to everyone in a very enlightening way. Also, the importance of taking these medications regularly and on time.

Anita Lloyd was an inspirational speaker to many too, as she proceeded to share her journey with Renal Disease and the trauma for herself and her family of having to undertake Dialysis as a very young girl at 12 years of age – and of receiving 4 transplants over the years since this, with the most recent being from her brother, which is still going very well 2 years later. Her vigilance in caring for herself is paramount after knowing and understanding the heartache of rejection and its set backs in her life. What an amazing journey and inspiring words of encouragement to others travelling this road.

Jonathan and Marie Muhl were our final speakers and they shared a very emotional account of their son, with photos, and his tragic accident and being asked re Organ Donation – a huge decision at a very emotional time in their lives. They too inspired many with their talk with the Transplant Retrieval team, and of the patients who are living on through their wonderful gift of their son's organs. A beautiful family, who have enriched many through their donation of this awesome gift of life, influencing others who may be presented with similar circumstances.

Overall this was an extremely successful day with morning tea served on arrival and a luncheon served to break up the day and enable time to chat with one and all before the afternoon session started. A very enjoyable day attended by members and their extended families along with quite a number of interested folk from the community. Thank you again to all of our speakers – you made the day the success that it was.

Our next meeting is 1st August 2017 at 7:30pm at the Community Trust Rooms (back entrance), Don Street, Invercargill. All welcome.

Diane McLean - President / Treasurer - Southland Kidney Society Incorporated.

Thanksgiving Service

7 May 2017

Bi-annually, Organ Donation NZ holds a Thanksgiving Service in Dunedin for donor families and recipients to get together and remember those who have generously donated and those who have received organs. It is held at St Paul's Cathedral and it was pleasing to see that this year we had a great turnout and, as usual, very interesting and thought-provoking guest speakers. We heard from a family who had donated their sons organs and how he saved eight lives by this generous act. We then heard from a man who had received a double lung transplant and could now do so much more with his son and family. We listened to a heart surgeon from Auckland who talked about the effect on him when he removed a heart and then watches it beating in a new chest. The surgeon then proceeded to read a poem which I felt was very much worth sharing -

Remember Me by Robert Test

At a certain moment, a doctor will determine that my brain has ceased to function and that, for all intents and purposes, my life has stopped.

When that happens, do not attempt to instill artificial life into my body by use of a machine, and don't call this my death bed. Let this be called the bed of life, and let my body be taken from it to help others lead fuller lives.

Give my sight to the man who has never seen a sunrise, a baby's face or love in the eyes of a woman.

Give my heart to a person whose own heart has caused nothing but endless days of pain.

Give my blood to the teenager who was pulled from the wreckage of his car, so that he might live to see his grandchildren play.

Give my kidneys to one who depends on a machine to exist.

Take my bones, every muscle, every fibre and nerve in my body and find a way to make a crippled child walk.

Explore every corner of my brain. Take my cells, if necessary, and let them grow so that someday a speechless boy will shout at the crack of a bat and a deaf girl will hear the sound of rain on her window.

Burn what is left of me and scatter the ashes to the winds to help the flowers grow.

If you must bury something, let it be my faults, my weaknesses and all prejudice against my fellow man.

If by chance you wish to remember me, do it with a kind deed or a word to someone who needs you. If you do all I have asked, I will live forever.

The service concludes with donor families receiving a camellia aptly named "Donation" and the recipients lighting a candle in memory of their donor.



Some pics from OKS Luncheon (China Palace, May 2017)



KHNZ update May 2017

At the beginning of March 16 members of the Consumer Council met in Wellington to discuss the issues for kidney patients and their families throughout New Zealand. As always it was great to hear from those who have first-hand experience with renal failure, with their input we were able to identify the main issues that will be included in the manifesto which will go to Members of Parliament from all Political parties as part of election year. This will highlight and prioritise the work that is still to be done to ensure that the growing number of kidney patients in New Zealand receive world class medical care and support.

Priorities for this year's pre-election Manifesto include:

1. Ensuring the forthcoming deceased organ donation Strategy is adopted by Cabinet and, more importantly, adequately funded
2. Ensuring nationally consistent dialysis services across New Zealand – including
 - a. equity of access to 'out of district' dialysis for patients needing to travel,
 - b. equitable access to social work and other community-based support for patients dialysing at home, and
 - c. ensuring that patients on home dialysis face no additional costs than were they to be dialysing in-centre.

Mental health of dialysis patients, particularly those on home dialysis, is a concern, and another topic of discussion. Many home dialysis patients feel isolated having minimal contact with the dialysis unit. Some ideas of how this can be addressed included employing health care workers to visit patients in their homes on a regular basis – monthly would be enough, even if it was just to check in for a chat. A phone call once a month could also be another option.

Earlier referral for predialysis education was seen as important, to enable time for absorbing the information given. Another great suggestion was having renal clinic appointments early in the morning's enables patients to go to work or university etc.

The importance of advocacy and support for renal patients was highlighted, with upskilling of Primary care in CKD encouraged and needed.

Around 1200 Chronic Kidney Disease Management in Primary Care information packs have been sent out to GP Practices, we have had a large number of orders received already for KHNZ resources, and some education sessions booked. The GP summary guides have been reviewed and printed and are currently being distributed to GPs throughout the country. I have been doing a fair bit of travelling lately providing education to primary care staff keen to learn more about kidney disease and its management.

Carmel Gregan-Ford

New Zealand Kidney Exchange Programme

(by Fiona Ferguson, Renal Transplant Coordinator, Southern DHB)

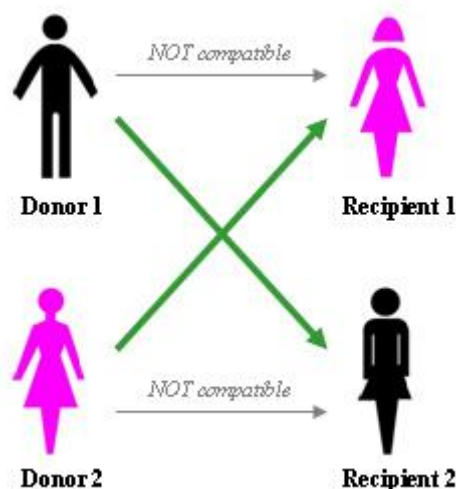
In April 2011, the first two-pair kidney exchange was successfully carried out in New Zealand. Another milestone in kidney transplantation in New Zealand occurred in October 2016, when the first three-way kidney exchange was performed.

What is kidney exchange?

A kidney exchange can also be described as a “kidney swap”. It is an option where a potential recipient has a potential living donor, but their blood groups do not match and the recipient has antibodies against the donor’s tissues. They are described as incompatible (they are not a match). Unfortunately, this means that the recipient is unable to accept the kidney from their donor as it would result in immediate, life threatening rejection.

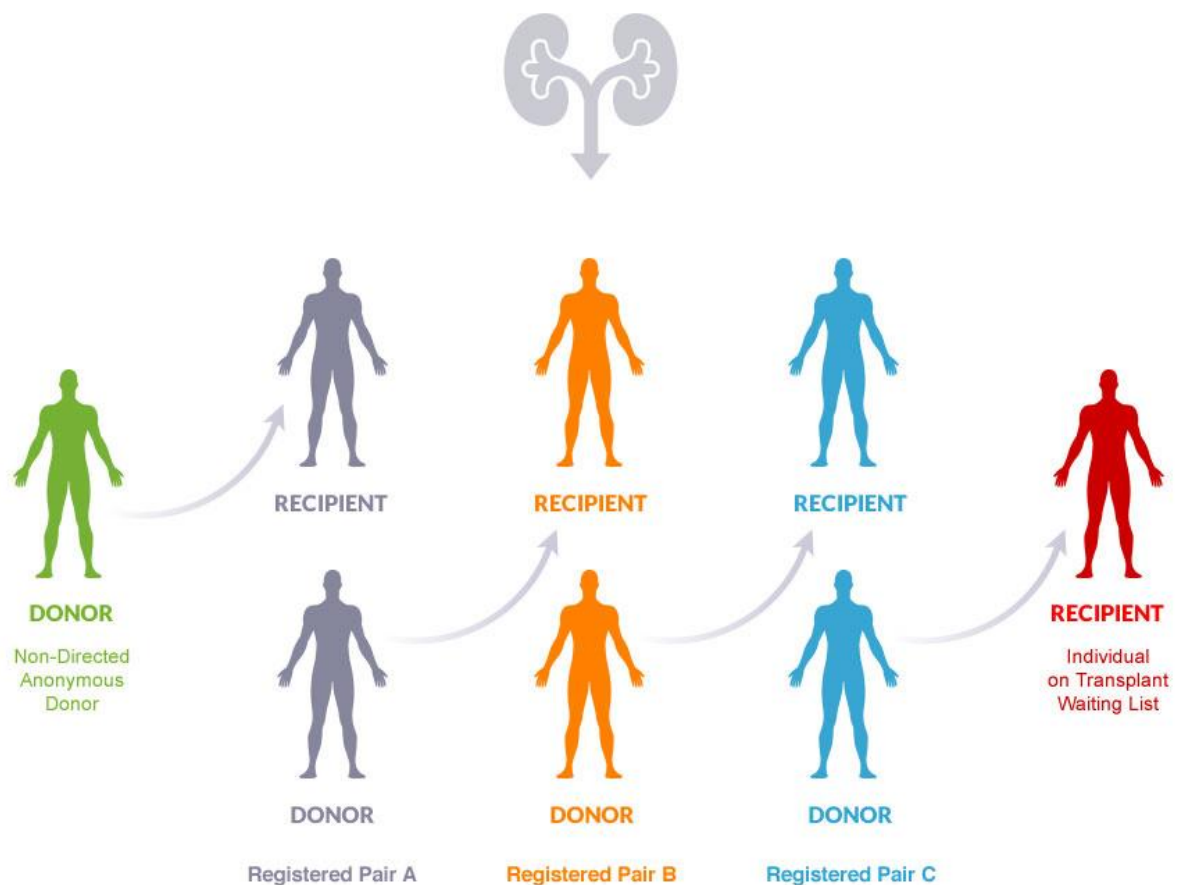
Historically, when this donor/recipient mismatch occurred, the recipient’s options were very limited if they were unable to benefit from a live kidney donor transplant, which is the “gold standard” in treating End Stage Kidney Disease (ESKD). The alternative for the recipient, if there were no other suitable donors and they were well enough, was to be activated on the waiting list. This did not and still does not guarantee a kidney transplant, as the current average waiting time can be up to five years with approximately 70% of those on the list never receiving a transplant.

The introduction of the Kidney Exchange (KE) Programme now provides another option with the goal to increase live kidney donor transplants by identifying compatible donors amongst other registered pairs who may be a suitable match and vice versa. It provides an opportunity for a recipient with a willing, but incompatible donor to receive a kidney, and results in at least two suitable living donor transplants (as seen in diagram below).



How Non-Directed Donors Fit in to the KE Programme

There are generous people who come forward as potential live kidney donors who do not have anyone specific to donate to, and they are referred to as non-directed (altruistic) donors (NDD). Prior to the introduction of the KE Programme, NDDs, if deemed suitable, would be allocated to a compatible waiting list recipient from the Transplant Unit where the donor assessment was undertaken. The New Zealand Kidney Allocation Scheme has now been updated to reflect the options now available to both live donors and recipients registered in the KE Programme. For instance, with the NDD's permission, their blood group and tissue type will be run through the KE data base to see if they are compatible with a "paired" recipient. This may result in the facilitation of two or more transplants via KE, instead of only one, and this is referred to as a "chain". This chain reaction starts with a sole, NDD donating to the compatible recipient in the first donor/recipient pair and so forth. At the end of the chain, there will be a sole recipient from the transplant unit who assessed the NDD, and who is compatible with the donor in the final pairing. This ensures that the transplant unit who assessed the NDD, in turn, has a recipient who indirectly benefits from the "chain" (as seen in diagram below). As for a deceased donor (DD) transplant, the donor remains anonymous to the recipient and vice versa.



The Future

Through the generosity of many New Zealanders, many people with failing kidneys have benefited from live kidney donation. The introduction of the New Zealand Kidney Exchange Programme overcomes the hurdle of incompatible pairings and offers recipients the opportunity to receive a compatible kidney with at least two recipients benefiting each time.

A NDD can now choose between donating directly to the best matched “wait listed” recipient from their transplant unit, or agree to be run through the KE data base to be matched with a “paired” recipient which may facilitate a “chain”. A NDD now has the potential of benefiting not only one recipient, but several. The aim of the KE programme is to also help reduce the imbalance between the significant demand for kidneys and their limited availability. This will hopefully result in a reduction in the number of recipients on the waiting list and see those recipients who aren’t fortunate enough to have a donor, transplanted sooner rather than later.

The New Zealand KE Programme pool is currently small, however, negotiations are currently underway to merge with the Australian Kidney Exchange Programme, which will significantly increase the opportunity for recipients to find a compatible donor. At this stage, tentative roll out date for the combined exchange programme is the end of this year so.....watch this space!

Contacts

Jo Burton is the KE Programme Coordinator based at Auckland DHB, however, for more information please contact Fiona Ferguson, your local Renal Transplant Coordinator based at Dunedin Hospital on a Wednesday or Thursday each week

Email: fiona.ferguson@southerndhb.govt.nz , Telephone 03 474 0999, Ext.58884 or 027 809 2575

Links

www.kidneys.co.nz

www.kidneydonor.org.nz

www.donor.co.nz

www.health.govt.nz

OKS - Lunch at Fat Harry's Mornington

Sunday 20th August

12.30pm



\$25 per person - set menu

Please rsvp to Liz Edwards (4554401), mob. 0210476187

or email: lb_edwards@extra.co.nz or Liz@oks.nz

By Wed 16 August 2017



Set Lunch Menu

\$25 per Person

Roast of the Day *(Pork or Chicken)*

Topped with gravy and served with seasonal roasted vegetables and steamed vegetables with white sauce

Sole Fillet

Battered Sole served with tartare sauce, salad and chips

Chicken & Bacon Salad

Lightly seasoned chicken pieces, bacon, crispy noodles, roasted cashew nuts on a fresh salad with a delicious BBQ mayo sauce

Ribeye Steak *(~200g)*

Cooked to your liking, topped with gravy, served with fries & salad

Crumbed Beef Schnitzel

Topped with gravy, served with fries & salad

Desserts

Mud Cake

Delicious chocolate mud cake coated in ganache, served warm with ice cream and whipped cream

Cheesecake

Served with ice cream and whipped cream

Ice Cream Sundae

Vanilla ice cream with your choice of chocolate, caramel, passionfruit or strawberry topping with fresh cream, marshmallows and wafers