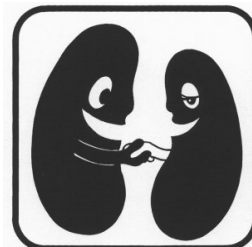




The Christchurch Kidney Society (Inc.)

Patient Support Group

SERVING THE LOCAL RENAL COMMUNITY FOR OVER 40 YEARS



The Renal Messenger

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Winter 2016

This issue has been funded by
Karen Faalilo, Property Transfer Office Ltd

FROM THE EDITORS DESK....

Welcome to Winter! Last week I definitely dug out the winter woolies, only to hunt for lighter clothes again today, as it is 19 degrees outside!

We are very grateful to Karen Faalilo, owner of the Property Transfer Office Ltd, for funding this edition. Karen is a member of the Society and on page 3 you can see what her company does and her connection to us - we wish Sam the very best for the future.

A reminder the CKS AGM is on Wednesday 22 June 2016 and we would love to see you there. It is a great opportunity to catch up with other members and supporters. There is no obligation to join the Committee if you attend, although new members are most welcome. Unfortunately we were unable to find a suitable date for Wyatt Crockett to speak, but there will be other opportunities in the future, this is a very busy time for him. There will be a special raffle just for those attending, refreshments and delicious finger food. **Doors open at 5pm.**

Speaking of busy.... Viv and I have had to rearrange the office, due to a fantastic donation received from Johnson & Johnson. We are so excited that we can “upsized” the contents of our care packs with donated sunscreen, lip balms, daily moisturiser and toiletry bags. We have also purchased new care pack tote bags, so Viv looks very stylish walking over to the Hospital now!

Another crazy cake stall was held on 27th May and we raised \$1234.80 on the day. The proceeds from this will be used to purchase additional “mini bikes” as the cycling group is expanding rapidly. Special thanks to all who helped and baked, and especially Rachel Morris for booking the stall.

In response to feedback from our members we are going to arrange a get together for transplant recipients and are always looking for new ways to support renal patients. If you have any suggestions or ideas, we would love to hear them.

Stay warm, Jo Houghton



The AGM is open to all
CKS members and the
public.

WEDNESDAY
22nd June 2016
**ANNUAL
GENERAL
MEETING**

Where: *The Home Dialysis Training Centre
Ground Floor Seminar Room
550 Hagley Ave, Christchurch*

Time: *Doors open at 5pm for refreshments
AGM 5.45 pm*

*The AGM is also followed by drinks with finger food and an
opportunity to catch up with members and guests.*

*To help us with estimating our catering requirements, please **RSVP** with the
number of people who will be attending by phoning the Kidney Information
Centre (03) 379 5529 and leaving a message, or emailing c.ks@xtra.co.nz*

Please RSVP By: 17th June 2016

"Conveyancers specialise in property and have specific training and qualifications in all areas relating to the sale and purchase of real estate and related transactions. Whether you are buying, selling or refinancing a property you can now use the services of a "Conveyancing Practitioner" Karen can be contacted on karen@propertytransferoffice.co.nz or 960-3004/027 208-1157.



I am proud to now be supporting the outstanding efforts of the Christchurch Kidney Society by sponsoring their newsletter. My family has been affected by kidney problems since the late 1960's with my father being diagnosed with Alports syndrome. He received a kidney in 1974 and this kept him alive long enough to live a reasonable quality of life and to see not only myself and my brother born but two grandchildren. Unfortunately, as a carrier of Alports Syndrome, I have passed this condition to my son, Sam. Sam is now 18 and attends Hornby High and proudly enough is this year's Head Boy. My husband Robert has passed the tests to enable him to be a donor to Sam (of which we are all grateful but nervous!). We are now waiting for the time that this kidney is needed - sooner rather than later for Sam who is trying hard to make plans for his future at University! Watch this space....

DONATIONS AND BEQUESTS:

A bequest of \$5,000 was received from the Estate of Pam Crawford. Pam was passionate about our patient support services and we will be able to continue these with this wonderful donation.

Funeral donations were received from the Estate of John Woolf (Father of Carol Woolf, former Renal Social Worker). It was very special to be nominated as recipient of funeral donations by John.

On behalf of the Executive Committee, I would like to thank everyone for their donations, they are greatly appreciated and are always allocated to our patient support services.



Johnson and Johnson Pacific (NZ) have donated over one thousand products to the Society for our care pack program. This is an enormous gift to the Society and we are very grateful and excited about the products we can now give to new dialysis patients, transplant recipients and live donors.

IDEAS FOR WINTER

It's that time of year again, the cold and damp has arrived so here are some ideas that might prove useful:

Have the window open a little in your kitchen when cooking and in the bathroom when showering., fan on if you have one.

Use bubble wrap on aluminium windows—cut to size, dampen the smooth side and stick to the window—no condensation. On wooden windows use DIY Window Insulation (available at hardware stores).

See www.scoopy.co.nz, these are available for stores or Community Energy Action at 299 Tuam St (Fitzgerald St end).

Mould a problem? Mix 70% white vinegar in 30% warm water and scrub off.

Further advice, products or curtains visit Community Energy Action (www.cea.co.nz) - they are a not-for-profit organisation and are very helpful.

NEXT POT LUCK LUNCH

We are taking a break from the 2 monthly lunches over Winter and will look at other options that may suit people better as they have not been well attended of late.

Watch this space!



P r e v e n t i o n • S u p p o r t • R e s e a r c h

Kidney Health NZ Consumer Survey

KHNZ is currently undertaking a major survey of renal consumers, kidney donors, kidney support groups and societies, and our 18 Consumer Council members. The purpose of the survey is to gain a better understanding of consumers' awareness of our organisation and the support/resources offered, utilisation of such support/resources, and where KHNZ could usefully expand the support/resources it offers.

The survey also touches on consumers' equivalent awareness of and engagement with their local support group/society – given that part of what KHNZ could potentially facilitate in the future is greater support and coordination of these local initiatives.

Here is the link to our survey:

<https://www.surveymonkey.com/r/VFDXGN9>

W E L C O M E

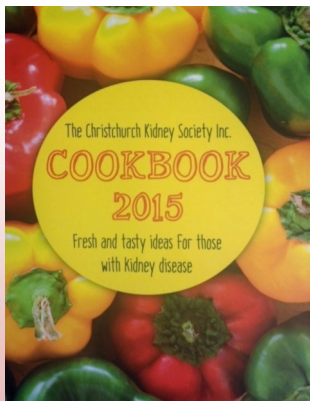


My name is Octavia Wilson and I recently joined the Nephrology Department as the Department's Clinical Psychologist. I work 20 hours per week for the Department, and the rest of my time I work at the Mothers and Babies Service, and in private practice at Resilience Psychology Christchurch. I also blog about psychology at www.resiliencepsychologychristchurch.com.

I'm originally from Christchurch, and trained at the University of Canterbury. I spent most of last year living and travelling in China and have settled back into New Zealand life in the past few months. I started working for the CDHB in February 2011 and have worked in different areas, including working with children and teenagers struggling with earthquake trauma and anxiety, and with young people experiencing psychosis.

I'm particularly interested in mindfulness, and work using Cognitive-Behavioural Therapy and Acceptance and Commitment Therapy. The part of my job I really enjoy is meeting new people and helping them work through difficulties and improve their mental health and well-being. Wishing you all the best and I hope to meet some of you in person!

OCTAVIA



COOK BOOKS STILL AVAILABLE

Price: \$10

Contact: c.ks@xtra.co.nz

or 03 379 5529 to place an order

Packaging and postage will be additional

The New Zealand Transplant Games Assn Inc.

MOVIE FUNDRAISING EVENT

THE CARER

HOYTS NORTHLANDS

Sunday 31 July 2016 at 6.00 pm

Dorottya is a young Hungarian actress with a burning desire to make it on the English stage. Legendary actor Sir Michael Gifford suffers from an incurable disease, and has one desire: be left alone. When Dorottya becomes his carer they both hope their wish will be fulfilled.

Members are encouraged to support this event and promote it to their family, friends and work colleagues.

Raising funds to assist members to represent
New Zealand at the World Transplant Games.

Tickets only \$25 per person

Includes lucky seat surprises

Buy a raffle ticket and be in to win a great prize!

7.30 pm prize draw.

For tickets or more information contact

Sara Ford: sarafor@clear.net.nz or 021 775 009

Join us for dinner after the movie

Rose & Thistle Sports Bar

8.00 pm, 24A Main North Road, Papanui

Red Lentil & Vegetable Soup (serves 8)

Ingredients

- 5 medium carrots, chopped
- 2 red onions, chopped
- 3 red peppers, chopped
- 5 cloves garlic, chopped
- 1 tablespoon ground coriander
- 1 tablespoon ground cumin
- 1/2 teaspoon ground turmeric
- Pinch of ground cayenne pepper
- 1 teaspoon Tabasco sauce
- 1 teaspoon Worcestershire sauce
- 300ml unsalted vegetable stock
- 250g red lentils
- 1.5 litres water
- 4 tablespoons chopped coriander



Steps

1. Combine the carrots, onions, red peppers, garlic, spices and sauces in a pot with the stock. Bring to the boil and simmer for 15 minutes until vegetables are tender.
2. Remove from the heat and puree.
3. Place the lentils and water in a large pan.
4. Bring to the boil and simmer for 25 minutes or until the lentils are tender.
5. Add the pureed vegetable mixture to the lentils.
6. If necessary, season with salt and pepper.
7. Stir through the chopped coriander.

Serve with a spoon of low fat, plain, unsweetened yoghurt.

Sourced from Diabetes New Zealand: http://www.diabetes.org.nz/food_and_nutrition/recipes

- 150g reduced-fat spread
 - 1/2 cup brown sugar
 - 2 eggs
 - 1 cup self-raising flour
 - 1 tablespoon cocoa powder
 - 1/2 teaspoon ground cinnamon
 - 1 1/4 cups feijoa flesh, diced
 - 2/3 cup dark chocolate chips
- (Serves 12)

Chocolate Feijoa Cake

Instructions and steps:

Step 1: Lightly grease and base line a 24cm-round cake pan. Preheat oven to 180°C. Cream spread and sugar together.

Step 2: Add eggs and beat until creamy. Add flour with cocoa and cinnamon. Fold in feijoas and chocolate chips until just combined.

Step 3: Pour into prepared pan and bake for 35-40 minutes or until lightly risen and firm to touch. Cool in pan for 10 minutes before turning out. Serve sprinkled with icing sugar and garnish with mint and feijoa.

Sourced from the healthy food guide magazine: <http://www.healthyfood.co.nz>

Hilary's Note: I have lots of feijoa's at the moment so am inspired to use in baking just to get through them. I suggest scooping out the middles and freezing excess feijoas for use later in the year.

Disclaimer

While every care is taken to insure the accuracy of information, views expressed in the Renal Messenger are not necessarily those of the Society. Articles by non professionals are intended to interest and inform and are not intended as medical or dietary advice. This information should come from the medical professionals involved in your care.

MY JOURNEY

My name is Lois Russell and I was one of four people to undergo a deceased donor kidney transplant in Christchurch on 26 March 2015. What a busy time for the awesome Nurses in Ward 14. I was originally approached to share my journey in July last year however I wasn't in the right space at that time due to complications. It has now been 14 months since my transplant and I am now in a good space and happy to share my journey. I was inspired after recently attending a moving Organ Donation Thanksgiving Service at the Transitional Cathedral and also seeing a piece on Seven Sharp regarding organ donation.

My journey began in June 2011 when I was diagnosed with IgA nephropathy with stage 4 chronic kidney disease. This coincided with the after shocks of the 13 June 2011 earthquake which didn't help my already high blood pressure. I was monitored regularly and continued full time work in a busy and stressful job however was feeling very tired, nauseous and often had a lack of appetite. I had an aggressive form of this disease and by October 2012 my kidney function had decreased significantly and I was advised I would need to have dialysis and go on a waiting list for a kidney transplant. I gave up work to reduce the stress in my life however continued to feel unwell through until February 2013 when I had an operation to have tubes inserted for Peritoneal Dialysis. I commenced CAPD in March 2013 which gave me a better quality of life with some brief periods of feeling unwell. I received awesome support from the Home Dialysis team. The hardest part of being on dialysis was the fluid restriction as you always want what you can't have.



After a few months I converted to using the "cycler" at night which gave me more freedom during the day. I started line dancing and Badminton which was good exercise and have met some lovely people. I also worked 6 hours a week as a volunteer Budget Adviser at the Christchurch City Mission. While on dialysis my husband and I travelled around the North Island with dialysis bags delivered to pre arranged accommodation points. We also travelled to Sydney and Melbourne which also went smoothly.

I went on the waiting list for a kidney transplant in March 2013 and at that time was informed that the average waiting time is about 4 years so you can imagine my joy to be phoned by John Irvine at 7-30am on 26 March 2015 that there was a compatible deceased donor kidney available. I checked into Ward 14 at 2.30pm and had the operation later that night. It was an emotional time for me and after the operation all I could think about was the donor and their family and what they must have been going through. I spent 8 nights in hospital still on dialysis while my new kidney kicked in. Once I got home I only had two more nights on dialysis as my kidney function improved. I attended the mandatory daily blood tests and clinics to see the Nephrology Doctors and enjoyed meeting other transplant patients and swapping notes regarding our progress.

My energy levels increased and it was great to be able to pass urine and have no fluid restrictions. I was fine until the beginning of June 2015 when it was discovered I had a blockage in the urether which caused fluid build up. I then became a frequent "visitor" to Ward 14. After trying a few options to clear the blockage it was decided I would need an operation to fix the problem. This was scheduled for 4 August 2015 however 2 weeks before this I got the flu and was very sick. I was admitted to hospital and fortunately this cleared up so the operation could proceed. The operation was a success however I ended up with a virus and some infections that required a number of return stays at Ward 14. My longest stay was 18 days when I was really sick however fortunately my kidney was still viable. At one stage I had up to 7 tubes and lines in me which wasn't pleasant. I really thought that I was never going to get better however after great care by the Doctors and Nurses I was finally well enough to go home. I had two more shorter stays in hospital with my last one being October 2015. Since then I have returned to line dancing and Badminton and recently started assisting my husband with his Real Estate business. I intend to get my Real Estate ticket later this year.

The hardest time for me was when I was really sick and in hospital for 18 days. At the time I was advised you will get through this and I did even though you don't think you will at the time. The tough times only make you stronger. Throughout my journey I have had amazing support from my husband and friends. I had six friends that wanted to be tested to be a donor - how amazing is that. One friend was a perfect tissue match however for health reasons he was unable to be a donor. He was devastated however it was only five months later that I received my transplant. By the way I named my kidney "Sidney" and

we had a first birthday party for him/her at the beginning of April. It was a special and fun time surrounded by family and friends who have been with me throughout my journey.

My pearls of wisdom from my experience are:

- *stay positive no matter how bad you are feeling*
- *accept help from others when they offer*
- *don't be afraid to ask for help*
- *talk to others who have been through the same issues*

I am keen to re connect with the other transplant patients I met at clinic in the early stages and have suggested to Jo Houghton that we have a social event for transplant patients. I hope you agree and will support this event if it proceeds.

I would like to thank Lois for her story and have had several requests lately to arrange a get together for those interested. The Nephrology Department has agreed to contact all transplant recipients for me, as due to the Privacy Act I do not know names and addresses of everyone, only those who are members of the Society.

I think "talking to others who have been through the same issues" is really important, and may be something that transplant recipients miss, once clinic times change and are extended over time. A social get together with recipients in different stages of their journey would be lovely to see.

If you are interested in a social get together, I would love to hear from you, so I can start to organise a time, date and venue. Please call me on 03 3795529, or email c.ks@xtra.co.nz.

MOBILE DIALYSIS UNIT (MDU) UPDATE:



NEWSFLASH

The use of the Society's campervan has been extended to all kidney patients. If you are interested in using the campervan, please contact us as we would rather it was used and enjoyed. Priority will always be given to haemodialysis patients, but if no bookings, it is able to be enjoyed by others.

IF YOU WOULD LIKE TO BOOK THE MDU CONTACT:

Dialysis Services

Christchurch Hospital

Ph: 3640 614

Or Email: Dialysis.workshop@cdhb.health.nz



Followed by.....

Just to let you know I have created a closed Facebook page for those who have an organ transplant, this is following on from recent conversations around post transplant issues some people are experiencing. It works the same way as the Kidney Failure uncensored page.

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

Carmel Gregan-Ford, KHNZ



EXERCISE UPDATE

The CKS Cycle Club is powering its way through Winter, all but one of the Peddlers are out so we will shortly be restocking. The Diabetes Centre had a demonstration and trial of a Peddler at their exercise class. They were so impressed that they now have some of their own! Our cyclists are finding them useful for both leg and arm exercises and no-one has complained of saddle soreness!

If you are interested in having one please do contact us and Viv will organize a trial if you wish.







MEMBERSHIP APPLICATION



APPLICATION To The Christchurch Kidney Society Inc.

FOR:

DATE:

☐ Membership

☐ Renewal of Membership

I/We, Name: Mr/Mrs/Ms/Dr)

Address:

Phone: ()

Email:

(Include your email address if you would like us to keep you informed about any events/information which falls between issues of our newsletter.)

Hereby apply for membership/renewal of membership of the Christchurch Kidney Society (Inc.), and enclose an annual subscription and/or donation.

Membership (includes immediate family) \$ 15.00 (inc. GST)

Donation (no GST, no obligation) \$

Total Enclosed: \$

If you prefer to pay membership directly to the CKS Inc. bank account:

Westpac Bank: 03 1591 0025801 000. Please include your name and initials in the reference. Please complete and return this form to the society to enable us to update our records and correctly receipt your membership with any donation you may wish to make.

Please tick all that apply:

☐ New member

☐ Dialysis Patient

☐ Existing member

☐ Transplant Patient

☐ Renal patient

☐ Supporter

I/We agree to abide by the rules of the Society.

Signature:

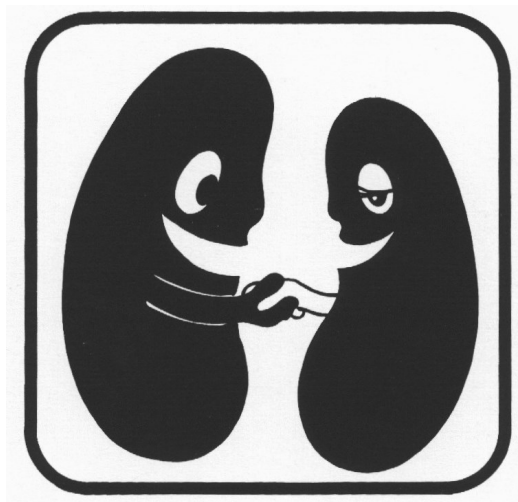
Please mail this completed form to: CKS, Level 1, 230 Antigua Street, Christchurch. Attn: Membership Secretary

The Christchurch Kidney Society (Inc.)

Kidney Information Centre
Level 1, 230 Antigua Street
Christchurch 8011

Phone: (03) 379 5529

Email: c.ks@xtra.co.nz



CONTACT LIST

Patron:	<i>Professor John Morton</i>	
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Vice President:	<i>Judy Giles</i>	Ph: (H) 3668054
Secretary:	<i>Jo Houghton</i>	Ph: 021 2860 309
Treasurer:	<i>Roger Sandford</i>	Ph (W) 366 6254
Committee:		
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	<i>Judy Giles</i>	Ph (H) 366 8054
	<i>Kathy Tuu'u</i>	Ph (H) 351 3401
	<i>Sara Ford</i>	Ph: (H) 980 2073
Nephrology Associates:	<i>Dr John Irvine / Dr Nick Cross</i>	
Field Worker/Membership	<i>Viv Smith</i>	Ph: (W) 379 5529