

The Christchurch Kidney Society (Inc.) Patient Support Group

SERVING THE LOCAL RENAL COMMUNITY FOR OVER 45 YEARS

THE RENAL MESSENGER



Spring 2023

Celebrating wonderful volunteers

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From the Editors Desk...

Dear Members and Supporters

Welcome to Spring, I always find it an exciting time with all the new growth and then weather that leads you to one day crack out the shorts and then the next your winter woollies!

We are very settled in our new premises and enjoying seeing people venture out to visit us and have a look around.

The can tab and wine bottle top collections have taken off and we are taking a load to the scrap metal dealers fortnightly. It is lovely to have Ray White Bishopdale collecting for us, along with the wonderful support of Lions Clubs from all around Christchurch and surrounding areas. We even have special bins in our reception area for members of the public who now know about it and call in regularly. It may not be a huge financial earner, but it is creating awareness and keeping it all out of landfill.

Our Bingo evening on 8 September was a sell out and was an evening of madness, laughter and fun (but I am not sure in what order?). We made a profit of \$7,235.00 and would like to thank everyone who came along, bought a raffle or auction prize and donated prizes for the evening. Huge thanks to Ethel & Bethel for their support on the night, and of course for the entertainment! Special thanks to Karen Faalilo, Property Transfer Office, for her incredible corporate (and personal) support, it made it a very successful night for the Society.

The focus is now on our annual Christmas Party which will be held on Sunday 10 December at the Hornby Club (because it was a wonderful place to have it last year) and invites will be sent out with this newsletter. If you know of a business or group that would like to contribute to this in any way, please get in touch. We have a basket set up in our reception area for non-perishable grocery items for our Christmas raffle and/or food boxes given out to those in need.

Best Wishes, Jo Houghton

Spoon Theory

#Spoonie



Have you seen the hashtag #SPOONIE and wondered what it meant?

The term spoonie is sometimes used to refer to a person with a chronic illness.

Spoon Theory is a popular theory that uses spoons to represent a unit of energy. The theory came about when Christine Miserando (who lives with a chronic autoimmune condition), was asked to explain what it's like to live with a chronic illness to a friend at a Café. Christine proceeded to use spoons to represent the amount of energy she has each day. For example: You wake up with 10 spoons for the day. Getting out of bed and showering uses 1 spoon, making breakfast might use another spoon.

As a person with a chronic illness, you have to work out how you spend the rest of your 8 spoons for the day. Sometimes you may use all your spoons and as a result have less spoons to start the next day.

The spoon theory helps explain how people with a chronic illness (spoonie) have to plan and ration their energy for the day. This is the difference between living with an invisible illness and being healthy, you have to constantly think about how you manage your energy.

Check out Christine's blog here.

butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory

GUEST SPEAKER: Transplant Gathering 28/10/23 SAM HIGH



My name is Sam and I'm a health and fitness professional. I specialise in helping others build thriving bodies so they can live quality lives.

I've suffered from kidney failure, been a dialysis patient, and undergone a kidney transplant. Now, 12 years after those events, I'm the healthiest, most thriving version of myself I have ever been.

I'd like to share with you the lessons I've learned during my journey from a fragile scared teenager on death's doors to a healthy, strong, thriving adult.

Health and fitness has been instrumental in improving the quality of my life. I wholeheartedly believe that everyone should have some form of health and fitness plan in their lives.

During my talk, we'll cover some of the best bang-for-buck methods that have helped me and my clients become stronger and healthier, both mentally and physically.

My goal is to have you walk away feeling more educated and empowered to start living your healthiest most thriving life yet.

I'm looking forward to seeing you all at the transplant gathering in October.

Guest Speaker Transplant Gathering 28/10/23



AARON SECREST

Aaron Secrest, MD, PhD is an academic dermatologist currently on leave from the University of Utah where he was a vice chair of dermatology. He is currently on a 2+ year sabbatical working at Christchurch Hospital in New Zealand. He has done extensive research on patient-centred care focused on improving patients' lives. Aaron's special focus is understanding what matters most to his patients and how patients' skin issues affect their quality of life.

He is very aware of how many patients have to pay more out-of-pocket for their care and their treatments. He spends time trying to identify the most cost -effective care for patients, even when the best treatment is over-the-counter.

To this end, he developed a website (<u>medicalsecrets.com</u>), which is a practical site for people to learn how to address common skin issues with the right over-the-counter options.

He completed medical school at the University of Pittsburgh, then worked as a paediatric house officer at Cincinnati Children's before my dermatology registrar training at the University of Utah. He is married with 6 children.

The Transplant Gathering (28/10/23) invites were sent out in August via the Nephrology Department. If you did not receive one and would like to come along, you are most welcome. Please RSVP by Monday 9 October 2023. Phone 3410906 / christchurch.kidney.society@gmail.com



We have some of the yummy Mamaku Blue 100% blueberry juice in the office for sale—\$33 for 1 litre, and no freight to pay. However if you would like to check out this product and the reviews, go to:

www.mamakublue.co.nz

You can also order direct and use the code "KidneyFriendly" (applied at the checkout) to receive 10% off our blueberry juice—it won't combine with other discounts. Use is one per customer, one use only. We have ongoing 7% off for all customers who decide to refer to a friend and/or 7% off for continuous orders.

We would also like to thank Mamaku Blue for supporting our Bingo evening

CHRISTMAS COLLECTION:

We are collecting items for our upcoming Christmas party and would appreciate donations of non-perishable grocery items and new items suitable for our chocolate wheel. Please drop donations into the office or ring us so we can collect them.

Every donation, no matter how big or small, is appreciated.



KIDNEY HEALTH NEW ZEALAND WELCOMES ANDREW BAKER AS NEW CEO

Kidney Health New Zealand (KHNZ) is delighted to announce the appointment of Andrew Baker as its new Chief Executive Officer. Following an extensive recruitment process, Andrew assumed his role effective July 3rd.



With a wealth of experience in leadership, ownership, management, and training across various sectors, Andrew brings valuable expertise to KHNZ. Notably, he has held senior management positions in the health, business, and leadership sectors. Andrew's most recent accomplishment includes lead-ing the Immunology Franchise at AbbVie, and the successful introduction of RINVOQ and SKYRIZI into the New Zealand market to support patients with severe rheumatoid arthritis and psoriasis.

Beyond his professional achievements, Andrew's personal kidney journey has contributed to his understanding of kidney health. Having overcome his own kidney challenge five years ago, he fully recovered and gained invaluable insight into the critical importance of kidney health. Reflecting on this experience, Andrew expressed his commitment to leverage his business and leadership skills to make a positive difference in the health outcomes of New Zealanders.

Andrew is enthusiastic about his new role and looks forward to returning to Christchurch to join the KHNZ team. "KHNZ is a highly respected New Zealand taonga. Leading it into the next phase is a tremendous honour," he said. After an extensive period in the corporate and pharmaceutical sectors, he is excited to be part of a small, impactful organisation that focuses on providing equitable access to end-stage kidney treatments such as dialysis, organ donation, and transplants for those with kidney disease. David Shearer, Chair of the KHNZ Board, praised Andrew's purpose and energy, emphasising that they align perfectly with the organisation's goals of advocating for systemic changes to improve renal equity outcomes for all New Zealanders.

Additionally, he expressed gratitude to Traci Stanbury, the Acting General Manager, for her unwavering commitment and significant contributions throughout the preceding year. She played a vital role in upholding stability and impact of KHNZ during this period of transition. The board is delighted Traci will remain involved to carry forward the valuable work she initiated.

About Kidney Health New Zealand (KHNZ):

KHNZ is a national non-governmental organisation (NGO) based in Christchurch, dedicated to representing the interests of the one in ten New Zealanders affected by kidney disease. The organisation strives to make a difference for kidney patients and their families by serving as the national voice for people with kidney disease and their families, advocating for worldclass kidney health in New Zealand, and providing reliable and relevant information on the prevention and management of kidney disease. KHNZ also commissions research to support its objectives.

As an independent national organisation, KHNZ is governed by a Board consisting of the Chair and up to six Board members. The organisation's stake-holders include individuals and families affected by kidney disease, kidney health professionals, researchers, and 22 independent regional kidney patient support organisations. KHNZ operates as a charity and relies on the generosity of donors, grants, and fundraising efforts. In 2019, KHNZ celebrated 40 years at Government House.

Disclaimer

While every care is taken to ensure 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.

ACKNOWLEDGEMENT AND THANKS TO:

- Grant and Marilyn Nelson, Gama Foundation, for 5 wonderful years at our old premises at Lunns Road. We are now fully settled in at 1/10 Yukon Place, Hornby, Christchurch 8042.
- The continued support from Pub Charity for our Field Worker's wages this will continue on until May 2024.
- MEMBERSHIP 2023/24: Our current membership year runs from 1 April 2023 to 31 March 2024. Our membership fee is \$15.00 and we are very grateful to all who pay this and those who add a donation. If this fee is unaffordable, please just let us know, it certainly does not exclude you from being a member of the Society. The first year of membership is always complimentary. It is amazing to have so many new members!
- The Society's bank account for membership payments and donations is
 03 1591 0025801 00.

The following organisations helped us along in 2023

The Lions Clubs of Wigram, Amberley District and Pegasus –Woodend

Carey Trust, Papanui Club, ChCh Casino Trust,

Ray White Bishopdale







Mini Exercise Bikes

We have peddlers available, please contact the CKS office—there is no charge, all we ask is that you return the peddler to us when no longer in use. These can be used for both arm and leg exercise.





Wristbands and Fistula Covers



The wristbands come in two sizes (21 cm and 24cm) and are printed with the words "No BP No Needles this Arm". The fistula covers are of various lengths and widths as well as colours. If you can spare a coin, to help us purchase additional material etc, that would be great—but not compulsory.

Fingerless Gloves

Pairs of gloves, sizes S,M,L, made of UPF 40-50 Lycra are available at office. \$4 for pictured length and \$3 for usual glove length. Also available merino gloves for covering post skin lesion treatment.

Concerning sun protection, from articles read, if specially treated fabric isn't available, it's best to choose darker colours, and tight-weave fabrics. Hold the fabric up to the light, if you can see through it the sun can get through it.



https://auckland-northland.cancernz.org.nz/assets/Sunsmart/Informationsheets/Sun-protection/IS-ProtectiveClothing-19Oct2011.pdf

RAY WHITE BISHOPDALE - Quiz Night

On the 15th August Ray White Bishopdale held a quiz night at the Papanui Club, with members of Canterbury Rugby. All proceeds from the raffle and sale of rugby balls were donated to the Society, total-ling \$714 and then we were surprised with a \$1,000 donation from the Papanui Club.

There was a huge crowd and while the Society's team (made up of Sara, Jo, Elaine Manson, Sarah Manson, Georgia, Maddie and Sam) didn't quite make the top teams, we didn't disgrace ourselves and came in mid field. However the Society certainly won with this lovely evening.

Having a business come to us and say they have planned something like this is absolutely wonderful, because not only does it help with our funding, it also creates awareness in our community of kidney disease. It was lovely to see some familiar faces in the huge crowd too.

Ray White Bishopdale is also collecting can tabs and wine bottle tops at their office too for our youth support programme.



OVERNIGHT DIALYSIS BY MARILYN NELSON

I have been on overnight dialysis for over two months and outline below the adaptions I have made to make the process easier.

When I first started using a Claria machine overnight for 9 hours we went out and purchased a 3 shelf trolley from Storage Box at Tower Junction. I then went to KMart and got 4 bins at \$8 each. The two bins on the bottom shelf are for each drainage bag. One of the middle shelf bins is for the emptied solution bags and the other bin is for all the tubes and bits and pieces that get cut off after the tubes coming out of each bag are clamped. The clamps are those I was given when I was doing dialysis 4 times each day.

When I wake up in the morning, the drainage bag in each bin is full so I clamp the tube near the bag and cut off the tubing and put it in the spare bin. I then put the empty fluid bag in a container on the middle shelf and also put in a partly emptied fluid bag in with it and then clamp it and cut away the tubing.

The trolley cost \$160. It is not essential but it does make the whole process quicker and more convenient. Having four containers does spread the load when lifting and makes it easier to deal with each bag.

The trolley is wheeled to a basin (or tub) and the containers are in turn lifted alongside the basin. The bag is moved to beside the plughole and the bag is cut close by using scissors. The screwed up empty bag is then put in a nearby rubbish container lined with a thick plastic bag supplied by Baxters. Once the rubbish bag is part full it is taken to our garage and later the next partly full bag is emptied into it and the full bag is tied up.

Our toilet is too far away so I have used a camping toilet at the end of the bed and found it very good. Once I am dressed I empty and wash out the small container.

The light on the machine was very bright so I taped a cardboard flap over it but I recently discovered that the light can be turned off from back at the office.

My machine is noisy at different times during the night and, while I have some ideas about how to reduce what I hear, I have not yet worked out the best way to deal with this problem.

If anyone else has experiences or tips they would like to share with others, please contact Jo.



Marilyn

AGM AND ANNUAL ACCOUNTS

We had a lovely evening at our recent AGM and welcomed new faces along, which was such a treat! Special thanks to Charlie (Ashburton Kidney Society President) and Esme Hill for making the journey from Ashburton to attend.

We welcomed Adrian Buttimore, as our new Patron of the Society and gifted him artwork by Jackie Hancock of Aroha Glass to acknowledge this.

Sara (Vice-President) chaired the meeting in Greg's absence and all positions on the Committee stayed the same—sincere thanks to everyone who is on the Committee and to most for their long service in those positions.

Our annual accounts have been reviewed by Aurora Financials, along with the CKS Graeme Cox Youth Education Trust accounts and these have been filed with the Charities Commission. You are free to view the annual accounts of both on the Charities Commission website:

https://www.register.charities.govt.nz/Charity/CC10927

https://www.register.charities.govt.nz/Charity/CC44975

We are forever grateful to Anna Morris, our voluntary accountant, for preparing our annual accounts for the review.

Special thanks to Karen at the Property Transfer Office for hosting our AGM.

Acknowledgement and thanks to our lovely volunteers at the office, we appreciate you all so much.

(from the left—Viv Smith, Sara Ford, Jo Houghton and Adrian Buttimore)



Featuring two very kidneyfriendly fruits, these mouthwatering mini pineapple upside down cakes are perfect for dinner parties or a backyard BBQ dessert.

Ingredients:

Serves 12

3 tablespoons unsalted butter, melted 1/3 cup packed brown sugar 12 canned unsweetened pineapple slices 6 fresh cherries cut into halves and pitted 2/3 cup sugar 2/3 cup fat-free milk 3 tablespoons canola oil 1 egg rsr 1 teaspoon lemon juice 1/2 teaspoon vanilla extract 1-1/3 cups cake flour 1-1/4 teaspoons baking powder 1/4 teaspoon salt

Instructions

Pour butter into a 12 serving muffin pan. square baking pan. Sprinkle a little brown sugar into each section.

Press one pineapple slice into each section forming a cup shape. Place one cherry half (cut side facing up) in the center of each pineapple slice and set aside.

In a large bowl, beat the sugar, milk, oil, egg and extracts until well blended. Combine the flour, baking powder and salt; gradually beat into sugar mixture until blended. Pour into prepared batter into muffin pan.

Bake at 180°C for 35-40 minutes or until a toothpick comes out clean. Immediately invert the muffin pan and drop the cooked cakes onto a serving plate. You can use a butter knife or small spatula along the edges if necessary to gently release them from the pan. Serve warm.







Try this Homemade Popsicle Ice Cube Recipe Makes 12 servings



Ingredients: Ice cube tray (tray hold 12 cubes) 1 cup Frozen mixed berries (blueberries, strawberries, and/or blackberries) 1 cup unsweetened almond milk Blender or food processor Popsicle sticks (Instead of popsicle sticks, use toothpicks, cheese spreader, or a straw)

Instructions:

- Place berries into a blender with almond milk.
- Mix contents together so it becomes a puree consistency.
- Place the puree into the ice cube tray and freeze.
- Check the cubes in about a half hour and place a popsicle stick in each cube. Let the cubes freeze fully and enjoy.

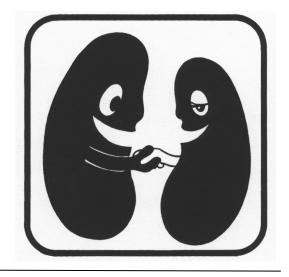
Flavor Options: For a sweeter taste, add sweetener or use other liquid of choice, such as juice, or other plant based milk

Please note that making any changes may change the nutrition content. https://www.rsnhope.org/renal-recipes/berry-good-homemade-popsicles/

The Christchurch Kidney Society (Inc.)

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