



Nobody can complain we didn't have nice weather this summer! We have all had to endure the very hot days we had in July. As I write this, we are due to experience another heatwave mid-August too. The weather will inevitably change as we turn the pages of our calendars and welcome in the Autumn. Children will be back at school, clocks will go back an hour and Strictly Come Dancing will be back on our tv screens again! If you were one of the lucky ones who managed to get away on holiday this summer, we'd love to hear about your experiences. Our contact details are on the back page.

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Organ Donation... and Beyond!

by – Chetan Joshi



Meet Jean Short. She's my kidney donor/ fairy godmother! Regular readers of this newsletter may recall an article I wrote way back in 2019 featuring Jean and the events that led to the serendipitous development of our friendship. You can view it online at www.westlondonkpa.org/newsletters-2019.

I am in total awe and have so much respect and admiration for this remarkable woman whose kidney has made itself at home inside me over the past seven years. For the past few years, Jean was the primary carer of her late husband Ken who sadly succumbed to dementia last year.

On a trip to Kew Gardens a few years ago, I asked Jean if I could (reverentially) address her as "Mum". She chuckled, "We only have one mum...but I'll be happy to be your fairy Godmother". We have kept in touch regularly ever since and not a week goes by without us chatting on the phone or emailing each other.



From left: The Queen, Jean and Celia

Jean is an avid gardener and I was fortunate enough to treat her and her friend Celia to tickets to The Chelsea Flower Show this spring where they both had a wonderful time.

It was during one of our phone calls earlier this year when Jean shared with me her intentions for her own onward journey when the inevitable happens.

"I've decided to donate my body to science when I die."

"GULP!" was my initial reaction. "Wow. Are you sure?" I asked.

"Yes. I've spoken with my GP and have been to see the solicitor to

get the ball rolling." She replied. I was totally dumbfounded. I have always considered Jean to be kind, sincere and generous. It turns out that she's also a very, strong, determined and courageous woman to boot!

Her GP linked her with Cambridge University who conducted the necessary evaluation and will take custody upon death. The body is usually kept for a period of time after which her ashes will be returned to her family.

It is her wish for her ashes to be placed by the tree where Ken's ashes were also placed.

Did you know that you can save up to NINE lives through organ donation?

Being a kidney patients' charity, the WLKPA focus on kidney donations. Live donation as well as cadaver donations are possible. More information can be found at www.organdonation.nhs.uk where you will find answers to questions that you may have or even discover more questions which you want to have answered!

It may just be a happy coincidence that this is the autumn issue of the newsletter and Organ Donation Week (ODW) will

These people have all had their lives transformed by organ donation



Right now, more than 7000 people are waiting for a transplant to change their lives.

As an organ donor you could save up to nine lives and transform many more by also donating tissue.

Add your name to the NHS Organ Donor Register, and let your family know what you've decided.

be celebrated from 19th-25th September. ODW is an opportunity for people to discuss the often sensitive topic of organ donation with family members and friends.

Probably the worst thing anybody could do is sit on the fence or bury their head in the sand. Nobody likes to talk about their own, inevitable demise. Remember that the laws on organ donation have changed in England.

If you don't want to donate, you must opt out. I'm

sure that we can all appreciate

that it can be difficult for medical professionals

to discuss organ donation with grieving family members upon the death of an individual. It's especially pertinent as some organs may need to be transplanted quickly to preserve their functionality after death.

It would be prudent to plan for such an event to prevent any embarrassment or heartache for those we leave behind.

To show your support during ODW, visit www.organdonation.nhs.uk for fundraising ideas or you can cut out and display the Heart-to-Heart mobile on page 13. If you fancy adding your own splash of colour, on page 14 of this newsletter there is a colouring in version of the Heart-to-Heart mobile.

Rising from the Ashes The new Charing Cross Dialysis Unit

by – Edwin Moabi



Amanda Pritchard visits Charing Cross Hospital to join Big Tea party on NHS birthday - Imperial Health Charity (imperialcharity.org.uk)

To commemorate the 74th anniversary of the National Health Service on the 5th of July, we had a visit from NHS England CEO Amanda Pritchard here at Charing Cross 1 South Renal Dialysis Unit.

There was a brief talk on the refurbishment of the unit following a devastating fire back in 2018.

The unit now predominantly provides dialysis treatment to Covid positive patients from the North West London Renal centres.

Ms Pritchard was impressed by how the unit engages with dialysis patients through the Imperial Health Charity Arts Engagement team which encourages patients to explore their creativity while undergoing dialysis treatment.



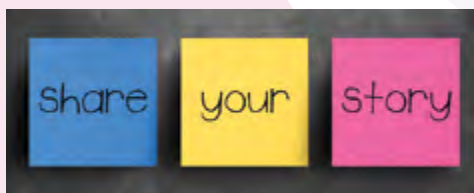
Introducing the London Kidney Network by – Jemma Reast



What is the London Kidney Network (LKN)?

The London Kidney Network is a network spanning across all London hospitals (including Guys) of kidney experts all working towards a common goal, improving kidney care in London. The network is made up of doctors, nurses, dieticians, physios, social workers and those with lived experience (patients and their caregivers).

The network's purpose is to improve access, quality, outcomes, value, and experience in kidney care across London. Within the network there are workstreams dedicated to the various aspects of renal care. This includes prevention, young adult care, dialysis, transplantation, supportive care, and the psychological side of CKD. Each of these workstreams are supported by expert groups in patient experience and health inequalities. This is to ensure those with lived experience of kidney disease are always front and centre.



Patient involvement within the LKN

Jemma Reast, who heads up the LKN Patient Partnership Group (also a renal patient, with lived experience of dialysis and transplantation) speaking on her vision for the LKN...

As Patient Partnership Engagement Lead, it's my job to ensure that, as a network dedicated to bettering renal care and management across London, we are always reminded of the NHS manifesto that puts patients and the public first - "no decision about me, without me".

Whilst there are many great burgeoning ideas and plans underway, these ideas tend to be driven by clinical staff, often without the consultation and involvement of the people it impacts most – us, the patients! Though the LKN already has some patients involved, we are keen to hear from as many people with lived experience as possible.

Without first knowing and understanding the patient experience (in all its varying forms), beyond our own perceptions and assumptions of it, how can the NHS design appropriate strategies, solutions, and steps toward reducing inequalities and improving the standards of care for London patients?

There are many ways, as individuals we can have a positive impact to the care, we, and others, receive in the future. The LKN hope to be able to provide easy avenues to do this via our Patient Partnership Group.

Sound up your street? Here is how you can get involved...

- Sharing your individual experiences of London kidney care – one to one or in a group setting
- Consulting and reviewing ideas, such as renal staff training documents or patient materials
- Working in collaboration with clinical staff to identify issues and areas for improvement and work together to develop real solutions on things that are important to you

There is an opportunity to make a real difference to the care you and other kidney patients in

London experience! Not only that, but there are also training and personal development opportunities available for those involved.

"Being a part of the London Kidney Network means I can voice and share my experiences and opinions about my care. It is important that doctors and nurses, and those commissioning services, hear about what patients go through, not just in terms of treatments, medications, dialysis, transplant, etc, but also in terms of experiences of patient transport, mental health, issues with housing, problems with welfare benefits, support at home, and other barriers to good health and wellbeing kidney patients may face. It is important for different hospitals in London to come together to share ideas, practices, and ways of working, so they can all be used to help everyone. The London Kidney Network is a great space to hear and be heard – patient and clinician alike!"
Patient rep in our health equity group

Get in touch for events, updates and wider London kidney info:

- jemma.reast@nhs.net
- Follow us on twitter @ LondonKidney
- Website coming in 2023

Healthy eating for Kidney Disease on a budget

by – Costanza Stocchi

With the recent spike in cost of living, most people are having to pay closer attention to what they are choosing to buy when food shopping.



While monthly bills, rent or fuel costs are increasing, the way we shop every week can be adjusted to help make room for other expenses. This is not easy, but our team has put together some tips to help guide your shopping and make budgeting your weekly meals a little easier without compromising on healthy choices. While monthly bills, rent or fuel costs are increasing, the way we shop every week can be adjusted to help make room for other expenses. This is not easy, but our team has put together some tips to help guide your shopping and make budgeting your weekly meals a little easier without compromising on healthy choices.

Try to shop local and seasonal

When you buy Spanish strawberries, kiwis from New Zealand or Italian oranges you will likely be paying for the cost of transport to get the produce into the UK. If a food is not in season, it will also be more expensive to grow - so it is cheaper to buy local and seasonal produce. On the plus side, seasonal food will taste much better!

The Vegan Society website has a list of all the produce in season throughout the year - It can be a

good idea to find out which fruits and vegetables are in season each month and to try and plan your meals around them. Please remember that some fruit and vegetables have a high potassium content (beetroot, tomatoes, spinach, mangoes, bananas...) so our advice is to try to limit these even if they are in season if you are trying to keep your potassium levels under control. Remember – frozen or tinned produce can also be cheaper than fresh, and just as nutritious: it can be a way to get closer to your 5-a-day.

Add pulses to your meat

Meat is very high in protein, which is essential to preserving strength and muscle tone especially if you are on dialysis.

However, chances are meat will be the most expensive item in your shopping basket. You can get as much protein from pulses, like lentils, chickpeas, beans, for about one third of the price. Mixing some lentils in with your Bolognese, or some extra beans in with your chilli, or swapping your meat-based dish for a veggie alternative is likely to save you quite a bit of money in just a week.

Compare like-for-like in the supermarket

When food shopping, try to compare the price per kg or per 100g instead of the price of the single pack. Bigger packs are usually more convenient, but only if you are going to be using all of them. For example, it might be cheaper to buy loose apples than it is to get apples in a multipack.

Meal planning can be an ally in trying to save. Going into the supermarket with a shopping list can ensure you only get what you need, and planning your food for the week may make it easier to be careful about choosing low potassium, low sodium or low phosphate foods and

ensuring you are getting enough protein with your meals if this is what you have been advised.

When you plan your meals, think of recipes you could make using the hob, a microwave or a slow cooker: the oven is the most expensive cooking appliance, so using it sparingly could help you save on your energy bill.

<https://cookingonabootstrap.com/category/recipes-food/> have put together a handy list of recipes for £1 per portion, or less. Their Tofu Shashlik, Moonshine Mash, Chickpea and Tomato Brunch Loaf and even their Salad Bag Pesto are only some of the kidney-friendly recipes you can find on their website.

<https://vegsoc.org/cookery-school/blog/seasonal-uk-grown-produce/> has a list of all the produce in season for each month of the year!

Hopefully our article helped, but, if you are struggling with healthy eating on a budget and would like further advice, please speak to your dietitian or contact your GP.

British Transplant Games 2022 Roundup



The Westfield Health British Transplant Games took place this summer in Leeds. Congratulations to everyone that took part.

There were attendees from charities from across the UK taking part at this fun, annual event. You don't need to be a professional to compete. If you want to join the team and take part next year in Coventry, do get in touch. To view photos from this year's games visit flic.kr/s/aHBqjzZUin.



Christmas Cards 2022

This year we will only be selling our packs of Christmas cards through the post again. A variety of designs have been carefully chosen to appeal to different tastes and we hope you see some you like.

The Christmas card leaflet and order form should accompany this issue but if there isn't one or you know someone else who would like to order some packs then the form can be downloaded from our website at www.westlondonkpa.org/christmas-cards-2022. We will start posting orders out at the end of October.

We do have a small selection of stock left over from last year which we are selling at a reduced price. For further details email secretary@westlondonkpa.org



Reminder

**ALL PATIENTS WITH CHRONIC KIDNEY DISEASE
AND ALL THOSE IMMUNOSUPPRESSED**

Please get the annual flu vaccine AND the
pneumococcal polysaccharide vaccine

FOR CKD 4 AND CKD 5 PATIENTS

Please organise via your GPs the hepatitis B vaccine

Notification & Agenda of West London Kidney Patients' Association's Annual General Meeting

West London Kidney Patients' Association's Annual General Meeting will be held on Thursday 27th October 2022 via Zoom at 6pm

Agenda

- | | |
|--|--|
| 1. Welcome and Apologies for Absence | 6. Financial report and Presentation of Accounts |
| 2. Minutes of the AGM held on Thursday 21 st October 2021 | 7. Election of Officers and Trustees |
| 3. Matters arising from last AGM | 8. Constitution and change of status |
| 4. Declaration of Proxies held | 9. Any Other Business |
| 5. Chair's Report on the year's activities | 10. Q & A |

Only Members of WLKPA can attend the meeting. If you are already a Member and receive our Newsletter, kindly email chair@westlondonkpa.org or secretary@westlondonkpa.org stating you would like to attend.

If you have not already registered as a member of WLKPA, we will ask you to kindly fill in the Application form detailing your name, address, telephone number, email address and if you are Imperial College Renal & Transplant Centre (ICRTC) patient/carer/family/staff.

You could apply online at www.westlondonkpa.org/subscribe

Download, print and share your heart.



Cut out our mobile, then hang it in your window and make the pledge to talk to your loved ones about your organ donation decision.

Please keep any part of these hanging mobiles away from babies, young children and animals.

Every year our nurses see families in the difficult position of not knowing what their loved ones would have wanted.

Do your family know what you would want? Get your family talking about organ donation.

Share on social media using **#OrganDonation** **#LeaveThemCertain**

AUTUMN LEAVES SILHOUETTE PUZZLE

One of the coloured autumn leaves doesn't have a matching silhouette.
Can you find which one it is?



COFFEE
BREAK
PUZZLE

Download, print and share your heart.

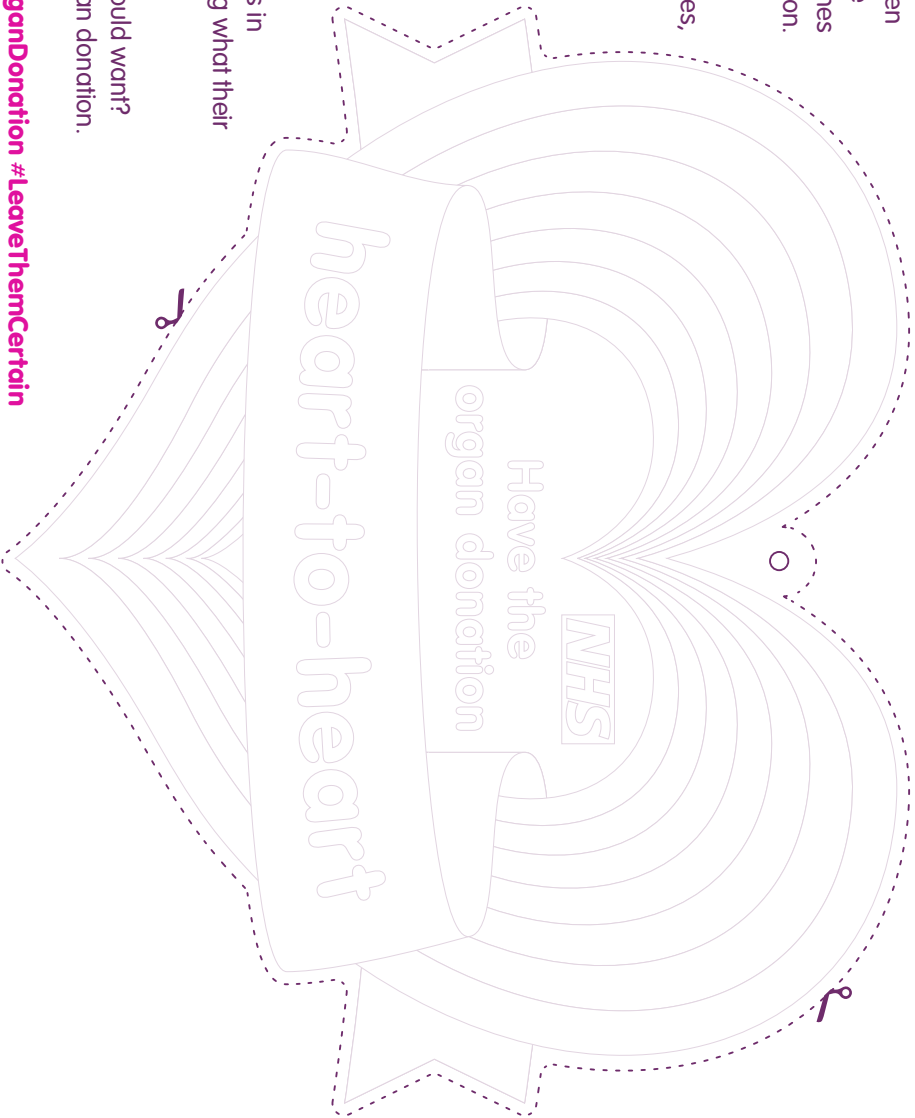
Colour in our mobile, cut it out, then hang it in your window and make the pledge to talk to your loved ones about your organ donation decision.

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Imperial College Renal & Transplant Centre

Contact Numbers

RENAL UNIT	TELEPHONE
Auchi Unit, Hammersmith Hospital	020 3313 6627
Brent Renal Unit, Central Middlesex Hospital, Renal Unit	020 8453 2017
Charing Cross Hospital , Renal Dialysis Unit, 1 South	020 3311 1752 / 020 3311 1034
Ealing Hospital, Renal Unit	020 8967 5737
Hammersmith Hospital , Renal Home Therapies (HD)	020 3313 6649
Hammersmith Hospital , Renal Home Therapies (PD)	020 3313 6647 / 020 3313 6665
Hammersmith Hospital , Renal Out-Patients' Clinic – Currently joined with St Mary's Hospital, Renal Unit	020 8383 8333
Hayes Renal Unit	020 37048 450 / 020 3704 8444
Northwick Park Hospital, Renal Unit	020 8869 3245
Pam Sassoa Unit (PIU), Hammersmith Hospital	020 3313 6682
Renal Dietitian, Nutrition & Dietetics	020 3311 1034
St Mary's Hospital, Renal Unit – Currently closed. Joined with Hammersmith Hospital, Renal Out-Patients' Clinic	020 8383 8333
St Charles Dialysis Unit, E & F Block	020 8962 5197/5196
St Charles Dialysis Unit, G & H Block	020 8962 4816/4815
Watford General Hospital	01923 217243
West Middlesex Hospital	020 8321 2543

Contact us: info@westlondonkpa.org

Or visit www.westlondonkpa.org

Winter issue Editorial Deadline:
18th November 2022

The West London Kidney Patients' Association (WLKPA)
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