

Supporting and working for kidney patients in West London

Registered Charity 275771

The West London Kidney Patients' Association

Newsletter

Spring 2024



Welcome to the Spring 2024 Newsletter.

We hope the year has begun well for everyone. I always begin the year filled with optimism and hope. I wonder at what the year has in store for me. One thing's for certain, there will be good times and some not so good but I'll definitely be wiser this time next year! A great man once said, "No matter how mundane life can be, every moment gives us the opportunity to become wiser."

Once again, we welcome articles for consideration in future issues of the newsletter from all of our readers. What pushes your buttons? What do you want to read about? Don't be shy. Email me: editor@westlondonkpa.org.

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The WLKPA Summer newsletter will be coming to you in June 2024.

To guarantee your FREE copy, subscribe online.

Article submisssions by 24th May



We need YOU and YOU and YOU!

We should have all settled into 2024 by now. New Year Resolutions will have been broken for many and the Easter bank holidays will be upon us soon. I have made a mental manifesto to give myself a tap on the shoulder and encourage more kidney patients (that's you lot!) to get involved with the WLKPA. I feel there are so many among us who can add value to what the charity does whether you are pre-dialysis, on dialysis or transplanted.

We want to aim to build a small team. A representative from each dialysis unit who can be a spokesperson or Point of Contact for their unit.

For example – We'd like to be able to host day trips again as we successfully did in the years pre-covid. Read past issues of the newsletter on the website to find out more.

However, due to the amount of man/ womenpower involved, it is prohibitive at present. We are unable to make several visits to each unit to put up and take down signs or posters and collect payment for tickets etc... Each Unit Representative would be best placed to reach out to fellow patients and act on our behalf for this purpose. It will also be a good way to get to know who else is in your unit and form lasting connections and acquaintances if you so desire.

In a previous newsletter, we reached out to welcome younger kidney patients who were joining us from Paediatric Services. We know that younger patients may be juggling education, work and family along with their kidney treatment. The transition from Paediatric to Adult clinics can be a little daunting at first. No kidney patient should feel isolated on their kidney journey. The WLKPA are here to help and there is a wealth of other help and advice available. We just have to tap each other on the shoulder once in a while to be the change we want to see.

Join Your Local Kidney Patient Association (KPA)

Supporting Local Kidney Patients & Families



Be part of your local support network

Your local KPA is

West London Kidney Patients' Association

Name: Sarita Khurana

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Tel: 07950758305

Kidney Patient Associations (KPAs) provide support for kidney patients on a local level and are members and the council of the National Kidney Federation (NKF).





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Birth of a Kidney Warrior - by Dee Moore

My journey with kidney disease started in the summer of 2018, after several weeks of feeling unwell and excusing the symptoms I was experiencing away, I started having headaches. This was the one symptom I could no longer ignore, and I went to A&E to get myself checked out. The Doctor ordered blood tests and when the results came back, she told me that I would have to be admitted.

One week into being admitted to hospital the Doctors told me that my kidneys were failing but they didn't know why. I was finally discharged 7 ½ weeks later with the diagnosis of stage 4 kidney disease. I had no idea then how my life would change forever. I assumed that I would simply "get better" but as the weeks turned into months and a treatment failed to improve my kidney function, I was confronted with the reality that my kidney disease wasn't "going away" it was with me for life.

In April 2019 I decided to start a Vlog on YouTube that I named, "Diary of a Kidney Warrior". I wanted to share my journey and what I was learning with others and hoped that this would help other people who were going through what I was going through and help give insight to their (and my) friends and family.

In May 2019 my Consultant told me that he believed that I was 6 months away from dialysis. I immediately and very defiantly told him, "No I'm not! I'm not going to be on dialysis in 6 months' time! I'm going to prove you wrong!" However, when I left the appointment, I became overwhelmed

with the fear of ending up

Coach Maxine.

on dialysis and how much

I had been through, and I went to see my Health Maxine sat and listened as I tearfully told her that "I've had enough! I can't take anymore!" and let out all my anguish. Then Maxine said something that literally changed my life, she said, "Dee, I want you to choose to live, and I want you to say these words: I choose to live". Maxine left the room. I sat in silence for what felt like an eternity, eventually I whispered the words, "I choose to live" and slowly repeated these words and got louder until I eventually shouted, "I CHOOSE TO LIVE!" Then something inside of me changed, a Warrior was born. Although I had taken on the name Kidney Warrior before, it wasn't until that moment that I felt a fight and a fire ignite inside me, and I was determined to do everything in my power to fight kidney disease. I started exercising again and changed my diet and I successfully fought off dialysis for 4 years.

In early 2020 my husband Roger asked, "why don't you start a podcast?" my response was, "what's a podcast?" I went and researched, spoke to my work colleagues who suggested podcasts for me to listen to and I soon realised that a podcast was exactly the format I wanted to share about kidney disease. I thought about what I wanted to achieve and why and I came back to my original intension, I wanted to share my journey and what I was learning with others, I wanted to help other people who were going through what I was going through. I was aware that I was very blessed to meet people very early on in my journey who taught me not just how to manage my kidney disease, but also how to cope with it. I was aware that unfortunately, not everyone had the network of support that I had and so I wanted the podcast to be a safe space for both kidney patients and health professionals to share their experiences, practical advice, and knowledge. Every subject possible would be explored so that all kidney patients would be empowered with knowledge to help them navigate their journey with kidney disease, but most of all, even if we were covering a subject that was very challenging, I wanted to always share a message of hope.

In August 2020, Diary of a Kidney Warrior Podcast was launched. In 2021 I was honoured to begin a partnership with Kidney Care UK and together we are continuing the mission of helping Kidney Patients, empowering them with knowledge and sharing a message of hope.

Diary of a Kidney Warrior Podcast is released every other Monday on Podbean, Apple Podcasts, Spotify & YouTube.



South Asian cuisine and kidney disease by Amman Beg, Specialist Renal Dietitian

Nearly everyone loves a hot and warming curry on a cold winter's day. You may be South Asian yourself or want to explore eating Indian and South Asian foods, whilst being on a kidney diet. This article will discuss how to eat South Asian foods healthily and safely for your kidney disease.

The Eatwell guide is a really useful way of eating healthily. It describes the main food groups and how much of these we should eat. In general, aim for half of your plate to be vegetables, with a quarter protein and the last quarter being starchy foods.



Starchy carbohydrates

Chapatti, roti, paratha, puri, basmati rice, grains like semolina, potatoes and breakfast items like upma, poha, idli and dosa are commonly eaten starchy carbohydrates in south Asian cuisine. Brown rice and breads will have more fibre than white ones and so are good for regular bowels.

To stop weight gain be careful with portion sizes for starchy foods and avoid using fats like ghee. A good tip is to use very little ghee or even avoid it! Try swapping to olive oil, rapeseed oil or sunflower oil, as these have good fats and less bad fats than ghee.

Potatoes contain a lot of potassium. Potassium is a mineral that makes our heart pump and it can build up in the blood when the kidneys are not working well, which can cause serious problems. If you have been asked to reduce your potassium intake, remember to boil potatoes and throw water away before adding to curries.

Protein & Dairy

Common protein foods are meats, dhal (lentils), chickpeas, beans, paneer, yoghurt (raita) and eggs. All types of dhal have protein, but some have more potassium than

others, so if you have to avoid potassium, try to soak dhal in water and throw this water away to remove potassium. You can then pressure cook the dhal as usual. Or you can use tinned dhals as these are already soaked in water. Some examples of protein-rich dishes include channa masala, anda bhujia, chicken tikka masala etc.

Dairy foods such as milk, condensed milk and yoghurt can contain a lot of phosphate, which can be harmful for those with kidney disease. You only need to limit high phosphate foods if your doctor or kidney dietitian have advised it.

Fruit and Vegetables

Fruit and vegetables are mostly eaten in south Asian countries in curries, salads or in raw form. They are packed with vitamins, minerals and fibre and 5 a day is advisable. Some fruit and vegetables have more potassium than others. If you are following a potassium restriction, try to avoid foods such as pomegranate, mangoes, dates, okra and karela. Tomatoes have lots of potassium, which can be hard to avoid when cooking a tomato based curry! Tips that help are swapping tomatoes to yoghurt for marinating meats and using blended peppers (capsicum) instead of tomatoes in curries.

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Snacks and Sweets

In South Asia, snacks and sweet foods can be given as gifts to celebrate Diwali, Eid or weddings. These are mithai (sweetmeats), halwa, jalebi, popadums, chutneys or samosas. These are a big cultural part of the south Asian diet, but can be high in sugar, fat and salt and so should be eaten in small amounts. For diet individualised advice, always speak to your kidney dietitian.

Salt is used in a lot of Indian and South Asian cooking and foods like chutneys, poppadum's etc may be quite salty. Salty foods can increase blood pressure so try to have no more than a teaspoon (5grams) of salt per day. An easy way to stick to this is to only use salt in cooking and not add any at the table when you eat. If you are on a potassium restriction, avoid using "lo-salt" as this contains potassium and can be harmful. You might find using other spices or herbs used in south Asian diet useful, for example, chilli

powder, coriander, garam masala, chaat masala etc, all provide distinct flavours and aromas. Experiment with them to find your favourite combinations!

Indian and south Asian cuisine offers a wide variety of choice, particularly for those following vegan or vegetarian diets. Dishes and meals are flavoursome and very economical, particularly if you are looking for delicious nutritious food that is low in additives, full of nutrients and packed with flavour.

If you haven't already, why not give it a go!

Scan this QR code to view the Kidney Kitchen South Asian Recipes magazine published by Kidney Care UK



British and World Transplant Games 2024

The Westfield Health British Transplant Games are set to take place this summer in Nottingham from 1st-4th August.



We are always keen to welcome new participants from across the spectrum of transplant patients in West London no matter how (un)fit or (un)competitive you

TEAM HAMMERSMITH may be. The minimum requirement is a positive attitude and the ability to walk or throw a ball! The games are equally about enjoying each others' company and making new friends from all across the UK.

Team Hammersmith are proud to announce that we have a new team manager – Peggy West is taking over the role and is assisted by Natalie Chiku, so If anyone is interested in taking part at BTG, please get in touch with them at Teamhammersmithmanager@outlook.com or call/ Whatsapp on 07957 213504.

Thinking long term... We do have high hopes of building a great team for BTG and have the resources to support a contingent of "athletes" for future events. We want to hear from anyone wishing to become a team member.

In other news...

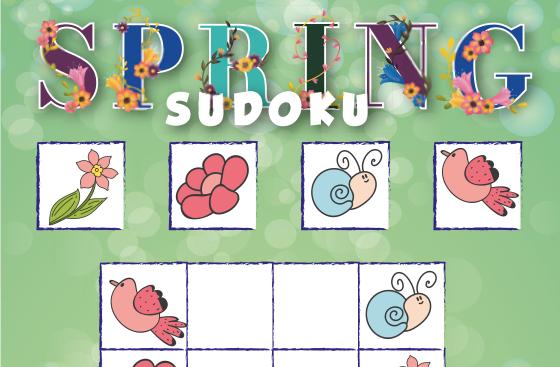
Bormio, Italy will be the host of the **12th World Transplant Winter Games** which are being held from 3rd to 8th March 2024. We are delighted to announce that we have some keen skiers among us who are/ will be swish-swishing their way down the slopes (hopefully to a medal!) We hope to bring you exciting news about their adventure in the next issue of the newsletter.



FIND THESE SPRINGTIME WORDS IN THE WORDSEARCH GRID BELOW?

BUTTERFLIES FXFRCISE MOWING **BFFS CALF FRIENDS ROBIN BLOOMING CHICKS SUNSHINE BLOSSOM GARDENING BUGS DAFFODIL TRAVEL HOLIDAY EASTER LAMBING TULIP BUNNIES**





Springtime Sudoku Puzzle

Fill in the Sudoku puzzle without repeating the images in the rows or columns



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	020 3704 6519 / 020 3704 6510
Watford General Hospital	01923 217243
West Middlesex Hospital	020 8321 2543

Contact us: info@westlondonkpa.org Or visit www.westlondonkpa.org

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