Supporting and working for
kidney patients in West London

Registered Charity 275771

## The West London Kidney Patients' Association

# Newsletter

Spring 2025


Photo by Yan Liu on Unsplash

Welcome to the Spring 2025 Newsletter – a little later than planned, but we're here!

Spring has sprung and with it comes a renewed sense of hope, energy, and the promise of warmer days ahead!  This season would be a good time to celebrate our strength, resilience and the progress we've made in managing our health.

Here are some ideas to help you bloom this season:

- Embrace the Outdoors – Can boost your mood
- Nourish Your Body – Eat fresh, seasonal produce
- Connect with Others – Share your experiences
- Prioritize Self-Care – Engage in activities you enjoy
- Celebrate Victories – Celebrate victories, big and small

## Contents

**The WLKPA Summer newsletter will be coming to you in June 2025.**

To guarantee your FREE copy, subscribe online.

Article submisssions by 16th May

## We need YOU and YOU!

**The West London Kidney Patients' Association (WLKPA) is embarking on another year of raising awareness, fundraising and supportng patients. We're reaching out to you, our valued community, for your continued collaboration and participation.**

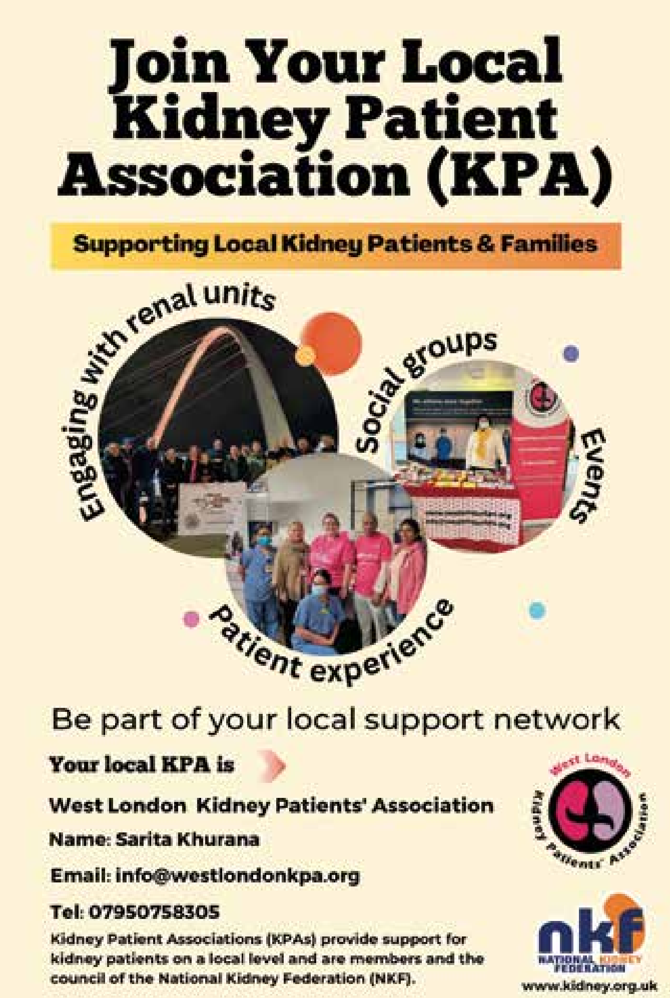
As we navigate the often challenging journey of living with kidney disease, spending countless hours undergoing dialysis and attending clinic appointments, it's easy to succumb to feelings of melancholy and despair, to feel trapped in an endless cycle of treatments and limitations. However, the WLKPA is here to remind you that you are not alone, that there is hope, and that together, we can overcome the challenges we face.

For those newly diagnosed, the apprehension and anxiety are completely understandable. Adapting to the significant changes in lifestyle and routine imposed by kidney disease can be daunting, a process that requires time, patience, and unwavering support. We all remember the adjustments we had to make during the pandemic, the unexpected disruptions and limitations that tested our resilience. The experience underscored the importance of adapting to change, even when those changes seem beyond our control. As an association, we firmly believe that it's crucial to not only cope with kidney disease, but to embrace it, to redefine our relationship with our health, and to find strength and resilience within ourselves.

The WLKPA is a patient-led organization, committed to helping each other not just survive, but truly thrive. We strive to create a supportive community where experiences can be shared, concerns addressed, and solutions found collaboratively. We are always keen to hear about the issues faced by our members, using their feedback to identify and address gaps in support, thereby enhancing the quality of life for all kidney patients in West London. Your voice matters, and we encourage each of you to actively participate, ensuring that your experiences, perspectives, and needs are heard and considered.

The WLKPA website will be undergoing a significant overhaul, and we invite anyone with design, writing, photography, or administrative skills to contribute their talents to this important project. If you can spare a few hours throughout the year to assist at fundraising events or help manage tables at our community gatherings, your support would be invaluable. Your contributions, large or small, make a significant difference.

To share your voice, offer your support, or get involved in any capacity, please contact Sarah Ilic at secretary@westlondonkpa.org. Your participation is vital, and we eagerly await your engagement.



**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**

**Email: info@westlondonkpa.org**

**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).

www.kidney.org.uk

## Life after kidney transplant failure

*– by Dr. Oshini Shivakumar*

**A kidney transplant is the best treatment for people with kidney failure because it helps them live longer and stay healthier.**

Even with medicines that help stop the body from rejecting a new kidney (like steroids and tacrolimus), some people still experience kidney transplant failure and need to return to dialysis. Every year, about 1 in 10 people starting dialysis had a kidney transplant that stopped working at the West London Renal and Transplant Centre (WLRTC). There is little research on how people who return to dialysis after a failed transplant compare to those starting dialysis for the first time, and the results from past studies are unclear. There are kidney clinics to help people whose transplants are failing, but once they start dialysis, they are usually treated in standard dialysis centers, where their specific needs might not get enough attention.

Our study looks at the health of people returning to dialysis after transplant failure compared to those starting dialysis for the first time at WLRTC.

Research already shows that certain blood markers, like monocytes (a type of white blood cell), and quality of life scores can help predict survival in people on dialysis. We want to see if these markers can also predict health risks in people returning to dialysis after transplant failure, especially those who have taken medicines like steroids to suppress their immune system. If these markers are useful, doctors can better identify high-risk patients and give them more focused care as needed.

The West London Kidney Patient Association (WLKPA) played an important part in shaping this project by giving important feedback last year. They felt it was an important project, and also suggested to look at how people feel when they have to go back to dialysis after a kidney transplant stops working. Their advice showed us that this is something not many people have studied before, but it matters a lot to patients. Because of their help, we have added a special part to our study to learn about the experiences of people in their first year back on dialysis. By listening to their stories, we hope to find ways to give better care and support to others going through the same thing. The WLKPA is also helping by giving money for a part of the project that looks at blood cells in a laboratory. This will help us learn more about how these cells behave in people on dialysis, who are exposed to medicines like steroids and tacrolimus.

We are very grateful for the Association's support and will make sure to keep patients and carers updated on what we learn. Their voices are important, and we want them to help guide our work.

## World Kidney Day 13th March 2025

As part of this year's World Kidney Day global campaign our KPA volunteers joined forces with renal clinicians at Hammersmith Hospital. They celebrated the importance of kidney health and raised awareness among the general public.

# Vaccines for Kidney and Transplant Patients: Why They’re Important and How We’re Making It Easier to Get Them!

*by Dawn Goodall – Transplant Pharmacist and*
*Dr Neill Duncan – Renal Consultant*

**Vaccines are a super important way to help keep our bodies safe from serious illnesses, especially for people with kidney problems or those who’ve had a transplant. But did you know that some vaccines aren’t always given when they should be? That’s something we want to change, and we need your help to make it happen!**

## What Vaccines Do Kidney and Transplant Patients Need?

There are a few vaccines that are really important for people with kidney disease or those who’ve had a transplant:

**Flu Vaccine** – Every year to keep the flu away.

**Pneumovax** – Protects against pneumonia, given every five years.

**COVID-19 Boosters** – To stay safe from COVID, especially in the spring and winter.

**Shingles Vaccine** – Protects against painful shingles.

## Why Aren’t They Always Given?

The problem is that sometimes vaccines are given only when you reach a certain age. For example, if you’re 65 years old, you might get a Pneumovax, but if you’re a dialysis patient who’s been on treatment for years, you should actually have received it much earlier.

The reason this happens is a bit tricky. It’s often because:

Patients’ health problems might not be recorded correctly at the doctor’s office.

Doctors may not always be aware of the special vaccine rules for kidney and transplant patients.

Since these vaccines are mainly offered by your family doctor (GP), it’s harder for specialists at hospitals to help.
But don’t worry,
we’re working on it!

## What’s Being Done to Fix It?

We are working with doctors, nurses, and health teams to make sure that you get the vaccines you need at the right time. Here’s how we’re improving things:

1. *Special Vaccine Lists for Kidney and Transplant Patients* – We’ve created a special list of vaccines that need to be given to kidney patients. This list is shared with doctors everywhere!
2. *GP Newsletters* – To make sure GPs know about these vaccines, we’re sending out a newsletter this December. They’ll get all the information they need to help you.
3. *Better Records* – We’re asking doctors to use special codes in their patient records, so it’s easier for them to see which vaccines are needed.
4. *Clinic Letters* – When you visit your doctor or clinic, we’ll make sure to include information about the vaccines you should get.
5. *Dashboard for Vaccines* – A new tool will help doctors track which vaccines you’ve had and which ones you still need. It’ll make things much easier!
6. *Special Teams* – We’re setting up teams to focus on getting the vaccines to the right patients, especially for those who need extra care, like transplant patients or those on dialysis.

## How Can You Help?

- **Ask About Vaccines:** If you’re a kidney or transplant patient, it’s a good idea to ask your doctor if you’ve had all the right vaccines. Don’t be shy – it’s your health!
- **Tell Your Doctor About Your Kidney Treatment:** Make sure your GP knows if you’re on dialysis or if you’ve had a transplant. This helps them give you the right vaccines on time.

Vaccines are a simple way to stay healthy, and with everyone working together, we can make sure you get the protection you need. We’ll keep you updated on any changes, and together we’ll make sure every kidney and transplant patient gets the vaccines they deserve!

# Thinking of travelling?

*by Anri Horne*

**The weather is changing, the days are getting longer and everyone is crawling out of their winter-duvet burrows. For some of us, as soon as we start preparing to throw ourselves into the warm, fragrant embrace of spring, we start dreaming of sunny vacations – be they trips abroad or local mini-adventures.**

For most renal patients - whatever therapy they are on - travel and holidays are possible and can be supported by the medical team, who will help with the arrangements. It is, however, essential that you check with your renal unit before planning or booking anything. Even if you have had a transplant you will still need confirmation that you are fit to travel in order to secure travel insurance and advice on immunisation.

## General travel tips:

- Plan far in advance - especially if you are a dialysis patient, last minute bookings are not realistic. Give yourself and your unit enough time to make all the necessary arrangements.
- Choose your destination smartly - it makes sense to ensure you are within reasonable reach of medical support in case of emergencies.
- Vaccinations - find out whether you need any vaccinations for your destination but check with your renal unit before having them as some may not be recommended for kidney and transplant patients.
- Medication – stock up on your medications and always divide your supply when travelling. Keep half with you in your hand luggage, and pack the other half in the luggage you check in or give it to a companion to carry.
- Sun Protection - make sure you take sunscreen with you and avoid overexposure to the sun. Sun protection is particularly important for dialysis and transplant patients.
- Food and drink - watch what you eat and drink. Talk to your dietitian about local foods to avoid before you go if you are worried.

## Food and drink to watch out for when travelling:

### Drinking abroad

(in countries with poor sanitation)

If unsafe, avoid tap water, ice, fruit juice and beverages made from tap water

Boil tap water before use or choose canned/bottled beverages

You may prefer to brush your teeth with bottled or cooled, boiled water

### Eating abroad

(in countries with poor sanitation)

Ensure hot foods are served piping hot

Avoid raw foods that may have been washed in tap water (fruits or salad)

Choose fruit and vegetables that can be peeled

## High-risk foods

Germs travel beyond borders, including to popular tourist destinations in developed countries. You can get sick from undercooked, raw and contaminated foods and beverages, especially if you are taking immunosuppressants. Some of these high-risk foods include:

- **raw or undercooked meat and poultry**
- **deli counter meat/poultry/fish**
- **raw fish and shellfish, such as sushi, oysters and caviar.**
- **meat, fish or vegetable pâté (tinned pâté is suitable to include).**
- **mould-ripened soft cheeses such as Brie, Camembert, certain goat cheeses, Danish blue cheese, Gorgonzola, Roquefort and Stilton.**
- **food that has been sitting at room temperature - this includes buffet foods, since food may not always be held at safe temperatures and can easily become mishandled.**

## Travellers' Diarrhoea

Travellers' diarrhoea is very common in travellers, and its impact can be severe and more serious in people with suppressed immune systems. To avoid this, wash your hands thoroughly with soap and water before eating or handling food, and always after using the toilet. Sanitising alcohol hand gel is an alternative when washing facilities are not available. Even if you play it safe and follow the rules for food safety, you still may find yourself feeling unwell on a trip. If this happens, stay well hydrated by drinking oral rehydration solutions and clean fluids.

For more information on how to stay safe and healthy abroad, visit www.fitfortravel.nhs.uk.

## In Memoriam – Dino Maroudis

**It is with sadness we bring you the news of the passing of our dear friend Dino Maroudias.**

Dino was instrumental in the formation of Team Hammersmith – the team name under which the KPA is represented at the British Transplant Games (BTG). During his time as team manager over recent years, he brought a fresh feeling of enthusiasm in all aspects of the planning and delivery of a successful games experience for all team members. Dino actively participated in many events during the games and embraced the inclusive spirit with which BTG is held annually.

## If you are interested in being part of the games…

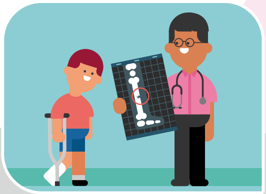
The British Transplant Games, a welcoming event in Oxford this year, invite transplant recipients of all abilities to compete in 26 sports and events over four days. More than just a competition, the Games celebrate the life-saving impact of organ donation, fostering a supportive community for recipients, their supporters, live donors, and donor families. Registration for BTG Oxford 2025 closes soon; don't miss this opportunity for new experiences and camaraderie.

For enquiries, please contact Peggy West at:
Teamhammersmithmanager@outlook.com
or call / message her on 07957 213504.

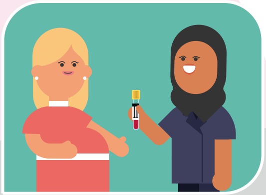
Care
Information
Exchange

NHS

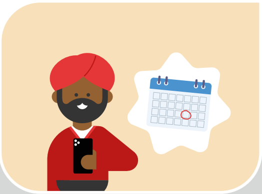
# Your online health records



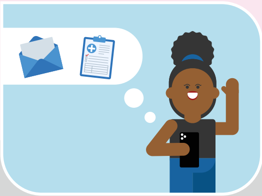
X-ray and scan reports



Blood test results



Appointments



Letters and discharge summaries

**Adults, children, and young people** can sign up on the Care Information Exchange **website** **www.careinformationexchange-nwl.nhs.uk**

**Adults** can also sign up on the **NHS app**

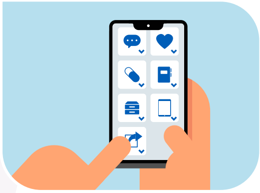
# Key details of your care. All in one place.

The Care Information Exchange gives you secure online access to your hospital health records.

- **View** your blood test results
- **Read** your X-ray and scan reports
- **Find** your letters, discharge summaries, and appointments

**You can add** information such as symptoms and fill in questionnaires.

**You can share** your health records with your family and carers if you want to.



The Care Information Exchange is powered by **Patients Know Best**.

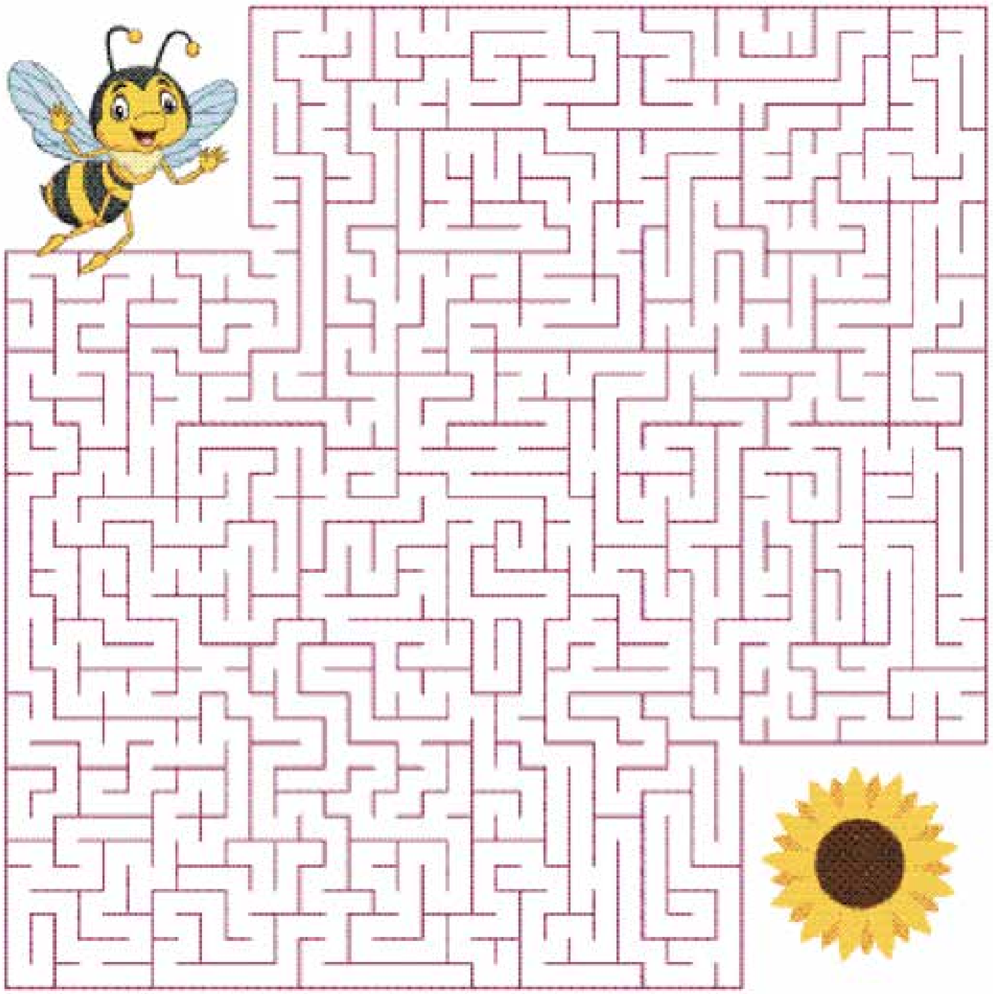
## How do I sign up?

**Adults, children, and young people** can sign up on the Care Information Exchange **website** **www.careinformationexchange-nwl.nhs.uk**

**Adults** can also sign up on the **NHS app.**

# SPRINGTIME MAZE

Can you help Bertie Bee find the way to collect pollen from the sunnflower?



# SPRINGTIME LETTER TILES

**Unscramble the tiles to reveal a message.**
**Each tile is used only once.**
**Use spacing, puncuation and common words to find adjacent tiles.**
**Some words may be split into two lines.**
**(Answer is at the bottom of the page)**

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## DID YOU KNOW...?

While many associate spring with the vernal equinox, which occurs around March 20th or 21st in the northern hemisphere, meteorologists define spring differently. They consider March 1st to May 31st as the spring season.

Also the start of spring is different in the southern hemisphere, where spring starts around September.

HYDRATION IS KEY IN WARMER SPRING WEATHER

# 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 3313 3048 |
| St Mary's Hospital, Renal Unit – Currently closed.<br>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**

The West London Kidney Patients' Association (WLKPA) Newsletter is published four times a year.*

If you wish to supply an article to be included in the newsletter, please contact the editor at **newsletter@westlondonkpa.org**. If you wish to subscribe to the newsletter go to www.westlondonkpa.org/subscribe.
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