

Supporting and working for
kidney patients in West London

Registered Charity 275771



The West London Kidney Patients' Association

Newsletter

Summer 2023

Welcome to the Summer 2023 Newsletter.



There were celebrations across the country for the coronation of King Charles III on Saturday 6th May 2023 and over the bank holiday weekend.

The WLKPA funded coronation festivities in the dialysis units, renal wards and clinics which everyone enjoyed as you can see in the photos over on pages 10-12.

Contents

Page 2-3

My Time On Dialysis
By Nicholas Bradshaw

Page 4-5

A Day In The Life Of
A Trainee Biomedical
Scientist (BMS-T)
by Kirti Kishorkumar

Page 6-7

Detecting antibody
responses to COVID-19
vaccines in immuno-
compromised people
by – Michelle Willicombe

Page 8-9

Kidney-Smart Dining
by Radiyah Choudhury
(Dietitian)

Page 10-12

Coronation Celebrations
Image Gallery

Page 13

World Kidney Day) 2023

Page 15

Coffee Break Puzzle

Page 16

Useful Phone Numbers

Autumn issue is due
out September 2023

To submit an article
for consideration.

Email:
editor@westlondonkpa.org

MY TIME ON DIALYSIS

by Nicholas Bradshaw

I only found out that I had one kidney in my sixties. Since then, it has deteriorated rapidly. When I was told that I needed to start dialysis, I thought my world would fall apart. So my wife Biffa and I booked in to the NxStage training centre in Kew to find out all about it.

My new home was the Home Therapies Unit at Hammersmith Hospital, who were all amazing and my first dialysis in 2017 was peritoneal which lasted until May that year. This consisted of two daily sessions at home and took about 45 minutes a time. So, I was able to carry on my life without too much disruption.

Unfortunately, by 2021 this dialysis was proving ineffective.

So the next step was to start Ambulatory Peritoneal Dialysis (ADP) which works overnight and my first thought was that this would free up my days completely which it did except for a booster bag late afternoon.

However, I must move around a lot in my sleep as I kept getting woken up by alarms usually two or three times a night!

Nine months on the ADP was not working as well as it should and the doctors recommended I transfer to Haemodialysis. This entailed visiting the hospital three days a week for a four-hour session of dialysis.

This was done at St Charles Hospital which incorporates a large and busy Haemo unit. With the travelling to and from the hospital and the treatment this basically took up most of the day.

However there was an upside to this as I was told that it was possible to have haemo at home.

Wow I thought freedom to plan my day and my week as I wanted – party time!

The plan was to train at St. Charles and I would be home after a few weeks happily doing dialysis as and when I wanted. I was introduced to Francis and Jae who were going to train me on all I needed to know about using the NxStage home dialysis machine. I started in February 22.

The reality was slightly different. As I previously mentioned St Charles is a very busy hospital and a lot of the time training was cancelled as they were short staffed and needed all hands on deck, Francis and Jae did their best and all the staff there deserve medals, it is a long and stressful day and they all work beyond their call of duty.

My training was on and off and Francis probably thought I was a bit slow in learning! Because of the intermittent training I decided to email Dr Duncan to see if there was any chance of getting a more consistent training.

Result! ... Yes, I could go back to my second home The Home Therapies Unit at Hammersmith, where Normandie and Eden under the

watchful eye of Adrian were eagerly awaiting to train me (and my long suffering wife Biffa) in the art of Home Dialysis. And train me they did. Four times a week I attended the hospital for intensive training on the foibles of the NxStage dialysis machine. By September I was ready to go home.



Once home one of the team came to our flat for the first few sessions which was really helpful as with anything new, there are always a few hiccups or alarms.

Another big advantage of home dialysis is that you can take the machine

away on holiday. We have access to a house in Cornwall and have been there several times. The result of all this is that I am now at home doing dialysis when it suits me.

A few tips: Get a comfortable chair preferably a recliner, I got mine from HSL and its VAT free if for medical purposes. Also a TV, an audio book or book are good to have around. A sturdy medical cabinet with draws and a suitable surface for preparation are just a few things to think of.

A Day In The Life Of A Trainee Biomedical Scientist (BMS-T) *by Kirti Kishorkumar*



The Leslie Brent Laboratory is a specialist laboratory dedicated to the development of methods to measure patient's samples containing drug medications such as Tacrolimus (TAC), Ciclosporin (CSA), Mycophenolic Acid (MPA), Sirolimus, Hydroxychloroquine (HCQ) and Anti-fungal drugs that help in the treatment of renal transplantation or renal disease.

I started my apprenticeship as a Trainee Biomedical Scientist in January 2023 and I start my day by checking the rota to see what tests are to be done that day and who will be doing them. We test TAC and CSA every day except Saturday and Sunday, alongside one or two of the other tests.

When patients attend clinic, their blood is taken into blood tubes and I go and collect these from the Renal Outpatient's Clinics and also pick up samples from Pathology Reception that have been sent there from the wards and outside hospitals. When I return to the lab, I hand them over to a junior staff member who books them in.

I then set up the machines (LC/MS analysers) that will be used for the days testing. I prepare solutions that are to be used on the analysers and also in preparing the samples before they go onto the analyser.

Next I label all the test tubes needed for the tests and prepare the work bench with the relevant solutions needed for the different tests to be done.

Depending on the rota I could be doing any of the different tests that I have been trained in, which so far is TAC and CSA, MPA and Anti-Fungals.



For the TAC and CSA tests, blood is taken from each patient's blood sample tube using a pipette and dispensed into a test tube along with the solutions I made earlier.



The samples are mixed, causing them to separate into liquid and solid, a bit like curds and whey, and are then placed into a centrifuge which spins the samples at high speed to separate the liquid from the solid. The liquid part is what we are interested in!



The test tubes are placed into a rack in the analyser to be tested.

Each sample takes 2.5mins to test and when the samples have been tested results are generated and evaluated for accuracy by a senior staff member.



There are a lot of checks that are made before results can be reported and if all the checks pass, results are sent electronically so that the renal doctors and nurses can view the results and then advise the patients on their dosages.

Towards the end of the day I clean and disinfect the workbench and work stations, replace any solvents and reagents used to their appropriate places. Clean any lab equipment used and restock supplies. Sometimes there are overnight runs and

in this case I make sure that there are enough solutions for the analysers and top up if needed. Finally the samples that have been tested are filed away and the lab is closed securely.

Detecting antibody responses to COVID-19 vaccines in immunocompromised people

by – Michelle Willicombe



Photo by Ed Us on Unsplash

Researchers within the Imperial College Renal and Transplant Centre are leading the nation wide MELODY Study, which aims to investigate whether measuring antibody responses to COVID-19 vaccines can help predict which immunocompromised people will become more unwell should they become infected. This may help inform who requires additional vaccines and who needs treatment, providing a more individualised management plan for patients.

How was the study run?

Researchers identified, contacted and recruited individuals with solid organ transplants (SOT), rare autoimmune rheumatic diseases (RAIRD) and blood cancers (BC) aged ≥ 18 years, resident in the UK, and who had received ≥ 3 doses of COVID-19 vaccine. Participants received an antibody test (a bit like a COVID lateral flow test) to perform at home, and completed an online questionnaire, in the first part of the study.

What was found?

We invited 101972 people, recruited 28411, and 23036 provided antibody data, comprising 9927 SOT recipients, 6516 with RAIRD, and 6593 with BC. Over 2/3 of participants had received four or more vaccines. We found that 23%, 14% and 2% of the SOT, RAIRD and BC participants had no detectable antibody responses to COVID-19 vaccines. In all groups, the detection of antibodies was associated with younger age, higher number of vaccine doses and previous COVID-19 infection. Immunosuppressive medication reduced the likelihood of detectable antibodies: the lowest odds of antibodies were found in SOT recipients receiving three different anti-rejection medications simultaneously, and those treated with anti-B cell therapy (e.g. rituximab) in the RAIRD and BC cohorts.

Interpretation

Approximately one in five individuals with SOT, RAIRD and BC have no detectable COVID-19 antibodies despite ≥ 3 vaccines, but this proportion reduces with sequential booster doses. Choice of immunosuppressant and disease-type is strongly associated with antibody response. Preliminary study data may be found in the following link:

Antibody prevalence after 3 or more COVID-19 vaccine doses in 23,000 immunosuppressed individuals: a cross-sectional study from MELODY | medRxiv

What will happen next?

The study participants were followed up for 6-months after reporting their antibody results. The study team will soon be analysing whether those participants with no detectable antibody were more likely to get infection and more likely to get more serious infection. The study team are hoping that the results will be available before the summer. If the study shows there is a relationship between antibody responses and infection, it is possible that antibody testing will become routine. Currently such testing is available at Imperial, but it is not available in all renal centres.

Gratitude from the study team

The research team at Imperial have significantly contributed to the evidence on protection of immunocompromised people from COVID-19. The team would like to thank the WLKPA for their kind donation back in March 2020, which enabled the initial purchase of COVID-19 antibody kits for testing. It was from this seed, the programme rapidly grew, informing local and national (where they could!) policy makers alike.

People with kidney disease continue to be more likely to contract Covid-19 due to their weakened immune systems. We continue to recommend that you should be vaccinated to help protect you. It is time for your spring booster vaccination which is available via your GP. Please refer to the Spring 23 vaccination update letter on the website for further information.

Kidney-Smart Dining

by *Radiyah Choudhury (Dietitian)*

Summertime with longer days and warmer weather may mean more outings, eating out and barbeques!

Eating out and ordering takeaways can be a challenge, especially when navigating dietary restrictions. With some planning and preparation, it's possible to enjoy a healthy meal out or a takeaway while maintaining a diet that works for your kidneys. In this issue we will discuss some tips for eating out in the context of kidney disease.

Plan Ahead:

- Before going to a restaurant, it may be helpful to look at the menu to see if there are any kidney friendly options.
- If you are eating out for dinner, consider planning breakfast and lunch at home accordingly, choosing foods that are in line with your dietary restrictions and needs, so that you can relax your diet a bit later in the day.

Choose wisely: When ordering food, opt for meals that are in line with your dietary restrictions.

- Choose grilled or baked meats instead of coated and fried. Opt for sides that are lower in salt - such as steamed rice instead of fried rice. If you are on a low potassium diet then choose lower potassium vegetable sides such as corn, cauliflower and green beans as opposed to mash or chips. Other good options include buttered noodles, pasta, bread rolls.
- Speak to staff about ingredients and preparation of dishes! Many restaurants are happy to make modifications to dishes or suggest alternative options.

Be mindful of salt/sodium: Salt can raise your blood pressure, lead to fluid retention and also make you thirsty. Most restaurants add a lot of salt to their foods, especially fast-food ones.

- Ask for your food to be made without added salt, salted butter, soy sauce, MSG (Monosodium glutamate). If choosing dishes which include salty ingredients such as capers and pickles consider alternatives or asking for these to be left out.

- Be mindful of hidden sources of sodium which may be found in some salad dressings/dips, heavily marinated dishes, and gravies – you can ask for these to be served on the side instead.



Fluids: If you are on a fluid restriction, remember to consider the amount of fluid you are drinking and in meals.

- If you know you will be eating out, adjust your fluid intake earlier in the day to accommodate the extra liquid you will consume.
- Consider liquid in meals e.g. soups, sauces, gravies and desserts such as ice-cream or those with custard and cream.
- Choose beverages carefully as beverages such as milky drinks, cola and some fruit juices, are high in potassium and phosphorus, which you might be trying to restrict. Stick to water or unsweetened tea and ask for a lemon or lime wedge to add flavour.

- Use portion control: Ask for smaller glasses for your beverage or request the server to fill your glass only halfway and request for this not to be refilled. Order your beverage by the glass instead of a pitcher.

Phosphate binder reminder! If you are on a phosphate binder, make sure to bring them with you when eating out and take with your meal.

In summary, eating out can be challenging for people with kidney disease, but with some planning and preparation, it is possible to enjoy a meal out while still maintaining a healthy diet.

Useful Links:

- The USA based National Kidney Foundation has a very interesting page on [Dining out with confidence](#). This is a handy guide on dining out with useful information on the do's and don'ts to help you enjoy mealtimes away from home with family and friends.
- www.kidneykitchen.org Kidney Care UK have developed an online resource of delicious, kidney-friendly recipes, approved by the British Dietetic Association.

Coronation Celebrations *(Continued on page 12)*

The WLKPA are very proud to have funded King Charles III's coronation celebrations in the dialysis units. We hope you were all able to raise a glass, raise a smile or raise a cheer where ever you were celebrating. Here are pics sent in from some of the units.



*Cherry Manilay
Head Nurse, Hayes*



*The Hayes Dialysis Team with
Sarah Ilic – KPA Secretary*

**"Thank you to the KPA for supporting us as always."
Claire Edwards – Northwick Park dialysis unit**



*Claire Edwards and Team
at Northwick Park Hospital*



*'Fruit cups! All the forbidden fruits to enjoy!'
Northwick Park Hospital dialysis unit.*



*Renal Home Therapies Unit,
Hammersmith Hospital*



*The West Middlesex Coronation Party
is in Full Swing!*



*The West Middlesex
Coronation Party treats.*

**"May I say a huge thank you to the
KPA for providing the funds to make
this amazing day so memorable
for our Patients and Staff."
– The West Middlesex team**



*Coronation Art workshop,
Auchi Unit, Hammersmith Hospital*



*Maura Applebe and Team
Auchi Unit, Hammersmith Hospital*

Coronation Celebrations *(Continued from page 11)*



Watford Dialysis Unit



Brent Renal Centre



Auchi Unit,
Hammersmith Hospital

**"Thank you for your generosity.
The patients and staffs really
appreciate it."
– Brent Renal Centre**



Auchi Unit,
Hammersmith Hospital



Renal Out-Patients Clinic,
Hammersmith Hospital

World Kidney Day (WKD) 2023

World Kidney Day is a worldwide health awareness campaign that is observed every year on the second Thursday of March. The day has been observed every year since 2006 to raise awareness globally about kidney health.

The first World Kidney Day was celebrated around the theme of "Are your kidneys OK?"



*Our tables set up
at West London
Renal & Transplant
Centre (above) and
Hammersmith Hospital
(right)*



The theme for World Kidney Day 2023 was "Kidney Health for All – Preparing for the unexpected, supporting the vulnerable."

World Kidney Day has several objectives. It primarily aims to raise awareness about the importance of kidneys and their remarkable functions in the body.

WLKPA committee members, Sarita, Sarah, Kerri and Zara – Sarah's daughter, were happy to be able to meet people face to face again this year on 9th March. They chatted with people about kidney health and distributed leaflets. They met a young woman whose mother had a transplant that morning and were delighted to see some familiar faces too. They had a very positive day and we'd like to thank everyone who donated money to our charity.



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Registered Charity 275771

The West London Kidney Patients' Association Newsletter



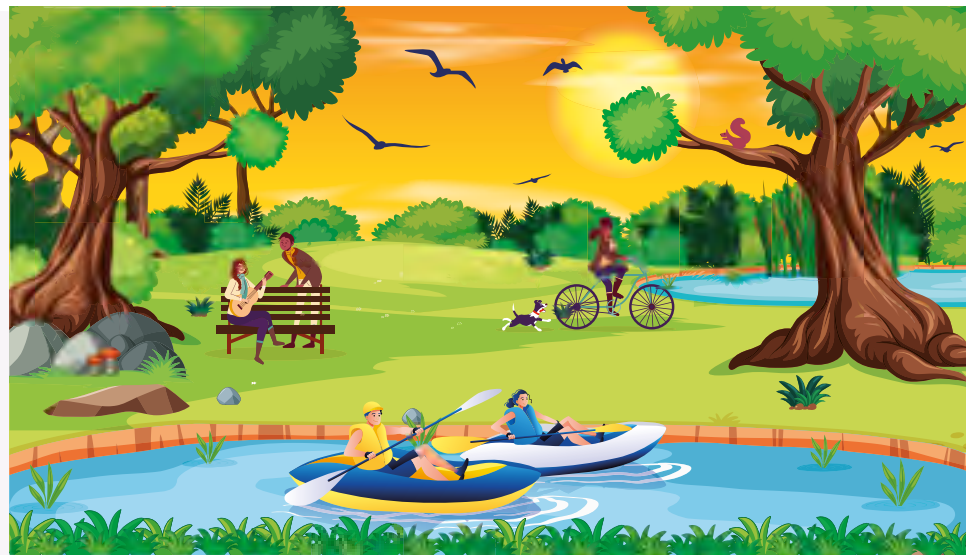
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Published four times a year and delivered straight to your door.* Each issue is packed with interesting articles, the latest news and developments in renal services that affect **all kidney patients** in West London who are under the care of the Imperial College Renal and Transplant Centre.

Get to know **your** Kidney Patients' Association and the work we are involved with at local and national levels. Become part of the community and if you've got what it takes, apply to become a volunteer/ committee member or contribute in a variety of different ways. Subscription forms are available online or ask a member of staff for a printed form.

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www.westlondonkpa.org

* Newsletters are also available to view and download from the website www.westlondonkpa.org/newsletter-2021



Summertime Fun Spot The Difference Puzzle

Can you spot the **ten** differences between the two scenes above?

[\(Answers revealed on the website\)](#)



COFFEE
BREAK
PUZZLE

Imperial College Renal & Transplant Centre Contact Numbers

RENAL UNIT	TELEPHONE
Auchi Unit, Hammersmith Hospital	020 3313 6627
Brent Renal Centre, 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 Sasso 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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