



Supporting and working for
kidney patients in West London

Registered Charity 275771

The West London Kidney Patients' Association Newsletter

Autumn 2020

Photo by Julian Wan on Unsplash



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The year is flying by. Autumn is already here! So much has happened over recent months yet in some ways, it still feels like the year is just beginning. Perhaps it's because we've all been cooped up in our homes for the most part of the year. We are slowly emerging from Lockdown as the rest of nature is going in to hibernation for the winter ahead. It seems like only recently we were enjoying the blossom on the trees but now as I go for a walk in my local park, I see trees are already shedding leaves, acorns are falling to the ground, children are going back to school (or not in some cases) and there's a chill in the air. How times have changed! 2020 has certainly been a frightful

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rollercoaster for us. As the world scrambles to find a vaccine for the virus, we will have to get used to the fact that Covid-19 is here to stay for a lot longer than we would all like.

Our autumn issue is usually filled with fun things we did over the summer like our day trips which we had to put on hold this year. We will aim to update you on next year's itinerary as and when we can.

has had on the lives of kidney patients. We strongly urge you all to be mindful of taking the advice from government and also your Renal specialist, doctor/ nurse/ team.

The National Kidney Federation (www.kidney.org.uk) and Kidney Care UK (www.kidneycareuk.org) offer excellent advice on their websites if you need further clarification on best practise.



To get your hands on the Social Distancing Lanyard ask at your renal unit

Do keep your suggestions coming in. We want to keep our destinations as fun and varied as possible.

If you read our last (spring/ summer) issue, you'll know how some of us did our bit to alleviate the suffering of fellow patients struck down with the virus and how we provided support to our key workers on the frontline. As patients ourselves, we are all aware of the impact the virus

The NKF have produced a Social Distancing Lanyard for kidney patients to wear when out and about. The aim is to let others know that you require extra consideration with regard to social distancing. We have purchased over 3500 lanyards for all renal patients under the Imperial Trust. These have been distributed around the renal units so pick one up where you can.

Organ Donation Week 2020

Organ Donation Week this year was from 7th - 13th September. It gives everyone the opportunity to consider organ and tissue donation and fully understand the changes in the Organ Donation law that came in to effect on 20th May 2020.

All adults in England are now considered as having agreed to donate their organs when they die unless they opt out, have told their family they don't want to donate or are in one of the excluded groups: those under 18, people who lack the mental capacity to understand the new law, visitors to England, those not living in England voluntarily and people who have lived in England for less than 12 months before their death.



The poster features two red kidney-shaped balloons tied together at the bottom, held by a hand. Another hand is shown below, reaching up towards the balloons. The background is a clear blue sky with a hint of pink flowers in the bottom right corner. The NHS logo is in the top right corner.

The law around organ donation in England has changed

Organ donation remains your choice

To find out more about your choices, including how to opt out: visit organdonation.nhs.uk or call 0300 303 2094

2019124 © NHS 2020

Everyone still has a choice as to whether they want to be an organ donor and families will still be involved before organ donation goes ahead.

Whatever your decision, make your choice clear to your family and closest friends to ensure your choice is honoured.

David's Covid Journey

Meet David Atkins– one of our KPA colleagues and a professional chef as he recalls his personal account of being a Coronavirus patient.

It all started on 10th March. I was at work and we were all heading home as the kitchen was due to be refurbished. I had heard about the virus and as a precaution, I was already wearing a bicycle mask two weeks before Lockdown.

When it came to the 23rd, I went to dialysis as normal. Screening had not been introduced at this stage. Everything was normal. The following Wednesday, I was asked to come to dialysis early. As I entered, there were four other patients that were coughing and who were clearly not feeling well. Each of us had our temperatures read one by one. I noticed that I was positioned in between two patients that were poorly and who were instinctively removing their masks to cough. My temperature was 38.5. I was asymptomatic but I was told that I would nevertheless need to provide nose and mouth swabs. I complied and went home after dialysis as normal at around 8pm. The following day, I was called



by the doctor at around 4pm. He informed me that the results indicated that I was Covid positive. This was quite shocking to hear. I was instructed to go to West Middlesex Hospital the following day on Friday. I felt quite well apart from a slight temperature.

At the hospital, I was told to take Paracetamol on a daily basis. Over the following days, my temperature remained high and for some reason I was losing my appetite. I noticed that my sense of taste wasn't normal.

Whatever I ate, it tasted foul and I would end up throwing it away. That Wednesday I was 113.5kg. By the following Friday I had lost my sense of smell and taste and had developed a fever. My temperature upon arrival at dialysis was a touch above 38 degrees. I was beginning to feel weak. The weakness I felt was more intense first thing in the morning and last thing at night.

About 8 days in, on a Sunday, I was laying bed at home one morning. I was feeling so hot,

I was sweating buckets. The sheets were completely soaked and I knew there was something wrong. I struggled but couldn't get out of bed. I was so hot in bed yet the environment around me felt very cold. I stayed in bed the whole day. The following day, I felt really weak. However I managed to get myself to dialysis where I felt I ought to tell the nurses how horrendous I had been feeling. They inquired about my appetite as I had lost 7kgs in such a short amount of time. I told them that all I was able to eat was toast/dry bread and drinking honey & lemon in water. The only thing that gave me comfort during this time was a respirator that I use at home when sleeping as I have sleep-apnea. I really do think this machine helped me.

So, even in the second week, I still couldn't eat. My appetite was really bad. It took a further two weeks before my appetite came back and I began to feel better. Although the doctor had told me previously that I did still have the "R-gene" inside me, he was confident that my antibodies were fighting the infection. I was discharged back to the care of my usual hospital.

My life was slowly returning to a new-normal after a month. Sadly, it was a very difficult period for me. Within one month, I lost two friends to Covid-19 one of whom was a dialysis patient. Thankfully, I now have the reassurance of being tested whenever I go to dialysis and have my blood tested regularly. I still get bouts of depression but I'm glad the worst is over and I'm on the road to recovery.

#MakeADifference award nominee



Maura Applebe – Individual of the year

Head nurse,
Maura Appelbe,
has been
instrumental

in ensuring the best possible experience for patients using transport services at the Hammersmith Hospital Renal

Unit. From making sure patients with the greatest need do not miss essential appointments due to delays, to resolving issues quickly, Maura never loses sight of providing an efficient transport service for patients.

#ImperialThankYouWeek

#MakeADifference #ImperialPeople

#StaffAwards #Nominees #ImperialNHS

#WestLondon #WeAreTheNHS

Transplantation and Covid19

Our Transplantation programme was suspended in March 2020 as a result of the COVID pandemic.

After lengthy discussions with NHS England and our colleagues in the private sector, we were fortunate enough to re-start Imperial's Live Donor Kidney transplantation programme on the 2nd of July. We worked collaboratively with the London Clinic and successfully carried out six Live Donor Kidney transplants. The Live Donor service was paused during the summer to repatriate back to Hammersmith Hospital and is due to re-start on the week commencing 14th of September.

Our deceased donor transplantation programme recommenced on the 22nd of July at Hammersmith hospital and to date twenty-five deceased donor transplants have taken place. We are about to re-open the kidney-pancreas transplant programme as well at the Hammersmith site.

The team have been required to adopt new COVID appropriate working practices to ensure everyone's safety and well-being. There have been changes to the way we get patients ready for transplantation such as the need to develop online education and information resources. The team will keep you informed as these plans progress.

Funding request granted

The WLKPA are proud to have funded the purchase of chairs for the Patients' waiting area at the Watford Dialysis Unit.

Thank you to the KPA for their generous donation on purchasing chairs for our patients waiting room and clinic rooms. The chairs are very comfortable and patients are very appreciative of your ongoing kindness.

Kind regards
Helen



Christmas Cards 2020

You would be forgiven for wondering if it's **that** time of year again. Sadly, summer is over and we find ourselves gearing up for the run-up to the festive season. Mince pies are already in stock at some stores and it's only a matter of time before we find ourselves involuntarily starting to hum to our favourite Christmas tunes.

We have once again sourced a range of delightful Christmas Cards for this year. They include some seasonal favourites as well as new designs that will surely bring a smile to everyone's faces.

We will not be able to sell cards in our usual manner – at the entrance to Hammersmith Hospital this year, so hurry up and place your orders by post while stocks last. You'll find an order form enclosed with this newsletter or alternatively you can download one from our website at www.westlondonkpa.org/christmas-cards-2020.



Christmas Cards 2020
Support a local Charity this Christmas

Prices shown are per pack of 10 cards



Colourful Tree £3.00 ●

Size 116 x 160mm



Polar Bear Fun £3.00 ●

Size 108 x 108mm



Christmas Robins £3.00 ●

Size 116 x 160mm



Snowman Fun £3.00 ●

Size 160 x 116mm

All our cards are Royal Mail 'standard letter' size



Greetings as follows:
● Season's Greetings
● With Best Wishes for Christmas and the New Year

Enjoying Caribbean food on a renal diet by Anri Horne

Just thinking about Caribbean food sets my taste buds ablaze with thoughts of dishes full of tropical fruits and vegetables, seafood and salted fish, spicy grilled chicken and hearty vegetable-heavy stews, all topped with delectably sweet and tangy chutneys.

Unfortunately for some, many of these foods are high in salt and potassium. The good news is this doesn't mean you have to avoid this cuisine completely. Here are some tips on how to modify traditional Caribbean foods whilst managing healthy Potassium levels and avoiding too much salt.



1. Boil root vegetables (potatoes, yams, plantains, taro root, sweet potatoes and cassava) to lower the amount of potassium. After boiling them you can fry them. Note that all varieties of these vegetables are high in potassium. If your Potassium levels remain high even after boiling everything, consider eating potatoes more often than the higher-potassium yams and plantains.

2. For one-pot meals: boil the vegetables separately, drain off their water and then add them to stews or soups.

3. Soaking legumes and beans can also reduce the amount of potassium. Remember to take your phosphate binder if you are on one.

4. Eat fresh fish more often than salted fish. After soaking salt fish overnight, soak it again for two hours and rinse with loads of water before boiling it in fresh water.

5. Avoid added salt. Take advantage of the flavour of exotic spices and hot peppers. This is a great way of adding a new twist to your food without adding salt!



6. Find similar substitutions. When making a traditional Caribbean dish, try substituting the high potassium fruits or vegetables with lower ones. Peaches may be a substitute for mangoes, or strawberries for guava sauce. For leafy vegetables, try a cup of endive or escarole.

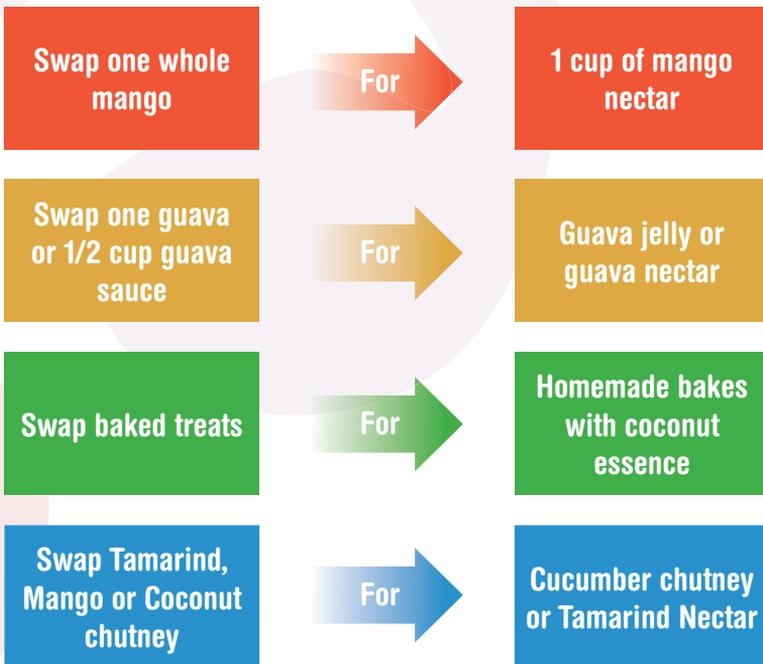
- 7. Opt for tinned foods. Some of the canned versions of Caribbean fruits and vegetables are lower in potassium than their fresh versions. Just drain off the liquid and rinse them before use to wash off any excess salt or potassium.
- 8. Avoid canned milk. Condensed and evaporated milks are much higher in Potassium; instead opt for fresh or long life milk.
- 9. Use maize fu-fu flour, as this is lower in potassium than the fu-fu flours made from plantain or cassava.



10. When dining out, don't feel too shy to inquire about the ingredients of the dish. Most likely the chef will be happy to make changes to meet your nutrition restrictions.

11. Missing coconut and bananas? Try using 1 to 2 drops of coconut or banana extracts found in the spice aisle of your grocery.

Here are some more swaps for you to try in your food preparation:



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 29 October 2020 via Zoom at 6pm

Agenda

1. Welcome and Apologies for Absence
2. Minutes of the AGM held on Thursday 24 October 2019
3. Matters arising from last AGM
4. Declaration of Proxies held
5. Chair's Report on the year's activities
6. Financial report and Presentation of Accounts
7. Election of Officers and Trustees
8. Constitution and change of status
9. Any Other Business
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.

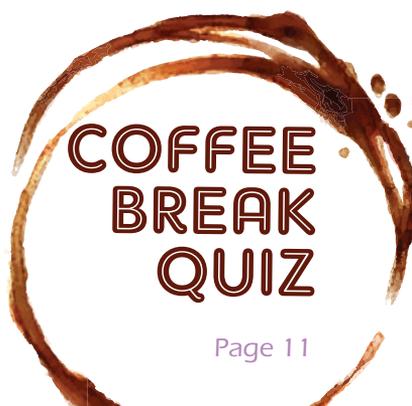
You could apply online at www.westlondonkpa.org/subscribe

Coffee Break Quiz

We've compiled a quizzical list of ten fun facts that'll surely make you scratch your heads. Answers are given below but don't cheat!

1. How long did the hundred years war last?
2. Which country makes Panama Hats?
3. From which animal do we get Catgut?
4. In which month do Russians celebrate the October Revolution?
5. What is a Camel's Hair brush made of?
6. The Canary Islands in the Atlantic are named after what animal?
7. What was King George VI's first name?
8. What is the colour of the "Black Box" in a commercial flight?
9. What is the main ingredient in Bombay Duck?
10. Which country has the world's largest Spanish-speaking population?

1. 116 years (1337 to 1453), Ecuador,
2. Sheep/horses
3. November (Russian calendar was 13 days behind Gregorian calendar)
4. Squirrel fur,
5. The dog (Latin name Insularia Canaria - Island of the dogs),
6. Albert (He changed it to respect wishes of Queen Victoria),
7. Orange
8. A variety of fish
9. Mexico (Said to have double the population of Spain).
- 10.



COFFEE
BREAK
QUIZ

Imperial College Renal & Transplant Centre Contact Numbers

RENAL UNIT	TELEPHONE
Auchi Unit, Hammersmith Hospital	0203 31336627
Brent Renal Unit, Central Middlesex Hospital, Renal Unit	0208 4532017
Charing Cross Hospital , Renal Dialysis Unit, 1 South	0203 31336627 / 0203 3111034
Ealing Hospital, Renal Unit	0208 9675737
Hammersmith Hospital , Renal Home Therapies (HD)	0203 3136649
Hammersmith Hospital , Renal Home Therapies (PD)	0203 3136647 / 0203 3136665
Hammersmith Hospital , Renal Out-Patients' Clinic – Currently joined with St Mary's Hospital, Renal Unit	0208 383 8333
Hayes Renal Unit	0203 7048450 / 0203 7048444
Renal Dietitian, Nutrition & Dietetics	0203 3111034
Northwick Park Hospital, Renal Unit	0208 8693245
Pam Sasso Unit (PIU), Hammersmith Hospital	0203 3136682
St Mary's Hospital, Renal Unit – Currently closed. Joined with Hammersmith Hospital, Renal Out-Patients' Clinic	0208 383 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

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

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

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