

## Breakthrough in organ preservation

Imperial College researcher Dr Karim Hamaoui reports on amazing progress with issues concerning organ preservation.

The dependency we have on organ donations is exacerbated by the reality that some organs that do become available are not fit for transplantation or might carry certain risks for a number of reasons.

Currently, organs are preserved with cold preservation solutions in an ice box but this may not be as effective in certain higher risk organs. Recently machine preservation has allowed organs to be preserved by dynamically pumping cold solution through the organ. The success of this strategy for kidney and liver grafts has kindled new interest in the use of

these techniques for the pancreas.

A study carried out using a novel technique called **pancreatic hypothermic machine perfusion** prolongs the life of a donor organ (the study was carried out on a pancreas), and can allow novel treatments to assess and improve its quality. The potential for this method is that the quality of the graft is better, which could beneficially result in greater survival rates and importantly an expansion in the number of suitable organs.

Dr Karim Hamaoui is a surgeon and honorary post-doctoral researcher at Imperial's Department of Surgery and Cancer.

Original article can be viewed at [wwwf.imperial.ac.uk/blog/imperial-medicine/2019/01/23/thinking-outside-the-ice-box-revolutionising-pancreas-transplantation/#more-1800](http://wwwf.imperial.ac.uk/blog/imperial-medicine/2019/01/23/thinking-outside-the-ice-box-revolutionising-pancreas-transplantation/#more-1800)

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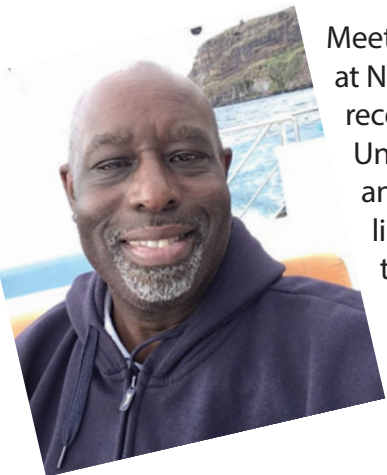
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## Our very own Ray of sunshine!

You may have observed from the abundance of holiday commercials that we see every day, that many people are busy at this time of year planning their summer getaways to sunnier warmer climes. Just because we are renal patients, doesn't mean that we should miss out on holidays with family, friends or even go on our own solo adventures. While it is very important to consider our health and any treatment that we may require, for some this is just another aspect of holiday planning just like making sure that passports and tickets are valid.



Meet **Ray Ellis** for example. Ray was on dialysis at Northwick Park Hospital for five years until he received his transplant in April 2018. Former London Underground Area Manager, Ray is a proud father and grand father who loves his holidays. In fact Ray likes to get away with his family whenever he gets the opportunity. We met up with him and asked him if he has any words of advice for other renal patients wishing to plan their holidays...

*Ray enjoying his holiday on a boat excursion  
Opposite page: Holiday snap of Ray and his wife*

### So Ray, how long were you on dialysis?

"I was on dialysis for five years. I started in 2013."

### You enjoyed your holidays before starting dialysis. How did going on dialysis affect your holiday decision making?

"Before I started dialysis, my wife and I visited Egypt, Tunisia, Gran Canaria... those kind of places. It didn't matter how sick I felt. I was determined to continue to enjoy my holidays. It wasn't fair on my wife not to go on holiday."

### So how did you go about arranging your holidays?

"I started to ask around to see what others were doing. I couldn't find anyone going on regular holidays. Some patients were visiting the St Annes Holiday Dialysis Centre in Hampshire while other patients were mainly going to India every couple of years to meet family. I wanted to go on proper holidays and sit by the beach. I went to the travel agent and asked about holiday dialysis. He was very surprised as he had never had an enquiry like this before."



He knew that dialysis patients were going on holidays and offered to do some research. He found a company called Freedom Travel. I contacted them and asked them how to go about arranging dialysis abroad? They said to choose a number of hotels at my destination and make enquiries about whether or not they provide dialysis. Find a hospital that is nearest to where you intend to stay. You don't want to be travelling for many miles and several hours three times a week to get dialysis. You're supposed to be on holiday after all! I would suggest a maximum driving time of half an hour should be fine. This is because, the local patients will usually get priority so you're not always guaranteed which shift you will get. Tourists will invariably get the 'twilight shift.' This is why I would also advise to book months in advance. There are no guarantees!

The first holiday we went on was to Spain. For the first two holidays, I had a Tesio line. I was told that most patients used a fistula.

Our first experience was a bit daunting as we didn't speak the language and had a lot of communication issues. Simple things like asking for a blanket was difficult.

I was offered a good meal though which was nice. There was a tv above my bed but I had no option but to watch local language programs even though the staff knew I wasn't Spanish. I had my pre-charged ipod so it wasn't all bad. They didn't allow me to plug anything in to the mains. My wife accompanied me on the first session but was abruptly ordered to go back to the hotel. I learned afterwards that it was their policy not to allow visitors in order to avoid infection. So my wife stayed at the hotel from then on, for further dialysis sessions."

### What else should patients be aware of?

"Well, all of the machines are different to what we are used to here, so don't be tempted to touch any buttons when the machines alarms. Cleanliness and hygiene can also be hit and miss. On subsequent holidays, I took cleaning equipment with

me from my hospital back home which I had packed in my luggage. I insisted they use the cleaning equipment I had brought to clean my machine whenever I went there for dialysis. It took them a while to understand that I wanted the same treatment as the locals but as I became a regular visitor, things did improve over time."

### Did you carry an EHIC card with you?

"I strongly urge anyone to get an EHIC card before they travel to some European countries. The first thing they asked me for when I arrived for dialysis was my EHIC card. This card entitles you to state-provided medical treatment. This must be taken out in addition to your regular holiday insurance. Who knows how things will change after Brexit?"

**Always check with your renal team that you are well enough to travel and get a Holiday Letter before booking your holiday.**

Due to space restrictions, the full interview will appear on the website along with Ray's email address if you want to get in touch with him.



The EHIC Card

## Recent Renal updates

We met with Prof. Vassilios Papalolis to discuss recent developments in renal research & services and their possible impact on patients.

The most exciting development was the machine perfusion project described in our cover story. Significant improvements are also taking place in other areas. In particular;

Polycystic kidneys can have major adverse effects on the health and quality of life of the patients involved.

The Trust has pioneered the successful removal of polycystic kidneys.

A wider range of living donor transplants are being carried out successfully, including high risk cases and transplantation before complete kidney failure.

Plans are in hand to increase the number of fistulae (for dialysis) quickly from its current low level by running a series of "catch up" surgery sessions on Saturdays until waiting times for the operation are substantially reduced.

Future research proposals will require a clearer demonstration of patient consultation and support if they are to be successful. The WLKPA will be consulted both about individual proposals and about priorities between competing proposals.

Finally the WLKPA is seeking to improve car parking arrangements for renal patients at Hammersmith Hospital, and is supporting wider proposals from the National Kidney Foundation.

## WLKPA Summer Day Trips 2019



Summer seems such a long way away, doesn't it? Can you believe supermarkets are already stocking cream eggs, treats that we normally indulge in during Easter? Well, in the same vein, we are pulling up our socks and rolling up our sleeves as plans get underway for our summer day trips 2019. Tickets will go on sale in the near future so keep checking the

website and be among the first to secure your places.

The destinations for this year are listed below. Due to the popularity of **Isle of Wight** last year, we decided to have **two** trips there this summer to avoid any disappointment. We have also added **Longleat Safari and Adventure Park** to the itinerary which is a new one for us and how could we not have **Eastbourne** and **Bournemouth** on the list? The annual airshows there, on the beach front, always draw huge crowds (weather permitting!)

Destination	Date
Isle of Wight	Sunday 7 <sup>th</sup> July
Longleat Safari and Adventure Park	Sunday 21 <sup>st</sup> July
Isle of Wight	Sunday 4 <sup>th</sup> August
Eastbourne	Sunday 18 <sup>th</sup> August
Bournemouth	Sunday 1 <sup>st</sup> September
Prices to be confirmed. Check website for updates <a href="http://www.westlondonkpa.org">www.westlondonkpa.org</a>	





## British Transplant Games 2019

Did you make a new year's resolution to get fitter? How did it go? For those of you who are determined to get more active or if you're lucky enough to already be in good shape, the **British Transplant Games** are set to take place this summer in Newport, south east Wales. Get the dates in your diary and register your interest. For those who are extra keen, the **World Transplant Games** take place in Newcastle the following month, in August.



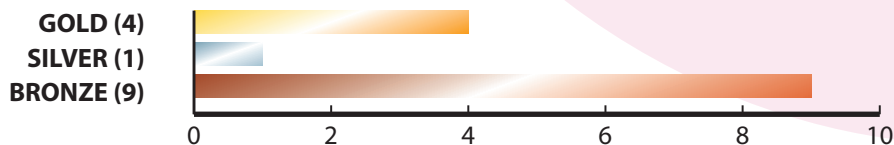
The British Transplant Games (BTG) bring the entire national transplant community, their families and friends together under the banner of sport. You don't need to be an expert to take part, newcomers are equally welcome to participate or even just spectate. Experts will be on hand to guide you if you're new to any sport or event. For further information, please see [www.britishtransplantgames.co.uk](http://www.britishtransplantgames.co.uk), you can also email the Team Hammersmith manager

Dino at [dinopremier@googlemail.com](mailto:dinopremier@googlemail.com) or the WLKPA chair Penne at [chair@westlondonkpa.org](mailto:chair@westlondonkpa.org).

### A LIST OF ALL THE SPORTS AND ACTIVITIES YOU CAN BE A PART OF

Adult Celebration Event	Children's Swimming	Golf Practice	Squash
Adult Short Tennis	Childrens 5 a side football	Indoor Bowls	Table Tennis
Adult Social Event	Childrens Celebration Event	Mini Marathon	Ten Pin Bowling
Adult Swimming	Childrens Cycling	Mini Tennis	Tennis
Adults 6 a side football	Childrens Social Event	Netball	Track & Field
Archery	Cycling	Obstacle Course	Under 5's Archery & Long Jump
Badminton	Darts	Snooker	
Basketball	Donor Run	Sport Stacking	Volleyball
Children's Ball Throw	Golf	Sportshall Athletics	Walk

Team Hammersmith won 14 medals in 2018. You could be part of the team this year and also be a winner!



## Kidney awareness talk at the Jamia Masjid Islamic Centre in Slough

**Members of WLKPA accompanied Consultant Urological Surgeon – Asif Raza at his first talk about kidney failure and prevention at the Jamia Masjid Islamic Centre in Slough.**



Asif giving his talk at the Islamic Centre

Asif said, "The hospitality we have received and the turn out at the meeting was very impressive. It was extremely useful to have Penne, David and Sarita present to bring my presentation to life and press home my message even more convincingly."



Asif with (from l-r) David, Penne and Sarita

We also had some kind donations from the mosque totalling £74.

I do hope this will be the first of many talks which we can take to places of worship for all our patients in West London. We are open to speak with any organisation that will invite us.

Prevention is better than cure in a lot of reversible cases due to hypertension and diabetes and hopefully with general education we will be able to improve awareness of kidney problems and how to avoid these and cope with dialysis or post transplant needs."

### Dates for your diary

Date	Event
14 <sup>th</sup> March	World Kidney Day 2019
6 <sup>th</sup> April	NKF Annual KPA Day
7 <sup>th</sup> Jul – 1 <sup>st</sup> Sept	WLKPA Day trips
25 <sup>th</sup> -28 <sup>th</sup> July	British Transplant Games 2019
17 <sup>th</sup> - 24 <sup>th</sup> Aug	World Transplant Games 2019
2 <sup>nd</sup> – 8 <sup>th</sup> Sept	Organ Donation Week 2019
October	NKF Conference 2019

Refer to website for full details  
[www.westlondonkpa.org/dates-for-your-diary-2019](http://www.westlondonkpa.org/dates-for-your-diary-2019)

## Quick meals on the go!

Article supplied by Elena Tsompanaki and Thushara Dassanayake

Food plays a central role in our lives. We talk, read and spend time during our day thinking about food. Being on dialysis can be a challenge when it comes to preparing meals; it can take up valuable time, particularly if you are travelling far for your treatment and you feel tired after dialysis. However, planning ahead can help overcome some challenges that should ensure that you are still able to enjoy food.

### Why should I bring in a meal or a snack with me on dialysis?

When it comes to eating well on dialysis, preparation and planning ahead can be very helpful, especially if you travel long distances. Eating while dialysing reduces muscle breakdown and so can help you feel better and fitter, live longer and improve your blood protein (albumin) levels.

### Should everyone eat something when on dialysis?

For some people, eating (particularly hot foods) while on dialysis can make your blood pressure drop. For this reason, if you are new to dialysis, you might be advised to wait some months till you are established. It is also better to avoid eating while on dialysis if you have a cough, low blood pressure, are sick and/or have diarrhoea or if you are feeling sleepy or not alert. If that's the case, then you can try eating something light 2 hours before coming to the dialysis unit.

### What can I eat when I am on dialysis?

Meal preparation can be quick if you know what to prepare. Here are some ideas:

- quick sandwiches with tuna, sweetcorn and lettuce, cheese, egg or chicken salad
- carrot, celery and/or cucumber sticks with hummus or Greek yoghurt
- crackers/bagel/pita bread and cream cheese (can be plain or flavoured with garlic, rosemary or chives)
- plain biscuits and cottage cheese and slice of tomato
- boiled egg on toast

- cup of homemade chicken soup
- unsalted pop corn
- toast, butter and jam or tahini
- sponge with custard
- fruit such as pear, apple, satsuma or tinned fruit cocktail
- egg and cheese with green salad
- pot of Greek or Icelandic yoghurt with honey and cinnamon
- cold couscous salad with boiled vegetables and cheese
- piece of quiche or flan
- cold pasta bowl with chicken/egg/cottage cheese/ beans/lentils



### I am on low phosphate and potassium diet and/or I have diabetes. Should I still bring in something with me on dialysis?

The foods mentioned above are suitable for all diets, however different people have different needs, therefore if you are on a low potassium or low phosphate diet, you may find it helpful to ask your unit dietitian for extra ideas or tips. If you are on phosphate binders or insulin, remember to bring these with you and take them as you would normally do.

If you have diabetes and experience low sugars (hypos), having a snack with you can be very handy to avoid hypos.

Regardless of what you take with you to eat while on dialysis, remember to enjoy food and stay creative. Good nutrition can help to improve quality of life and contribute to better health overall. To find out more, ask your renal dietitian.



## World Kidney Day 2019

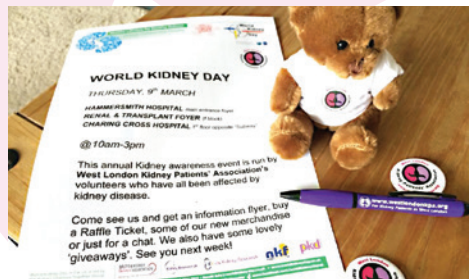
# KIDNEY HEALTH FOR EVERYONE EVERYWHERE



World Kidney Day (WKD) is an annual, global event that will take place on the 14th March this year. It first took place in 2006 and has continued to grow ever since. Its aim is to raise awareness of kidney disease and the importance of our kidneys. WKD also aims to help reduce the frequency and impact of kidney disease and its associated health problems worldwide.

It is estimated that across the world there are 850 million people living with kidney disease. Chronic Kidney Disease (CKD) is now the sixth fastest growing cause of death.\*

Across the world, hundreds of events take place from public screenings in Argentina to Zumba marathons in Malaysia. You can organise your own fundraising or awareness event / activity. Whether you wish to make it a solo effort or do it as a group, let us know so we can help make it a resounding success.



Check out our fantastic array of WKD raffle prizes on the back page!

\* Information taken from [www.worldkidneyday.org](http://www.worldkidneyday.org)

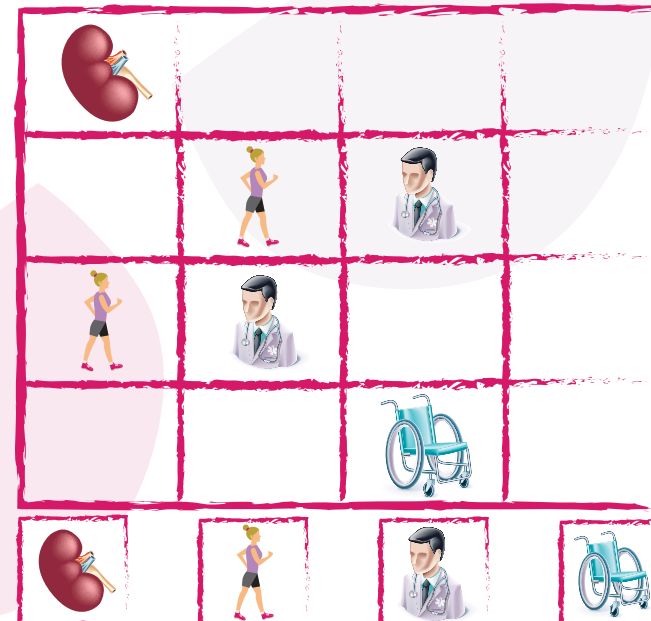
## Curry lunch fundraiser

Once again, the team from Dubai National Air Transport Association (dnata) raised funds for the WLKPA. This time, from a curry fundraising event held at dnata transport crew room at Heathrow Airport. The event was organised by renal patient Alex Mermezan along with his colleagues Ken Webb and Jas Singh who cooked the curry. They raised over £370.



## TS Racquet Tournament

The annual Transplant Racquets tournament 2018 saw Alex Mermezan win Gold in the men's singles racquet tournament. The aims of the Tournament are to create a greater awareness and understanding of the benefits of transplantation, and at the same time highlight the desperate need for more people to sign onto the NHS Organ Donor Register.



### Can you fill in this Renal Sudoku Puzzle?

Fill the grid with the four images below...but remember not to repeat the images in the same column or row.

Solution can be found on the website

# COFFEE BREAK PUZZLE

We've have received lots of very positive feedback regarding the revamped newsletter format. Nobody is perfect but that won't stop us aiming for it. We're a nice bunch of people, patients just like you. We strive to make a difference and always want to hear from you, our readers, about anything (renal related) that's on your mind or we would love to hear from you if you have a story or article you feel may be of interest to everyone else reading this newsletter.



*All in festive spirit! Ade (second from right) posing with Renal Staff members,*

Clinic attendees at Hammersmith Hospital were treated to a festive musical medley in December by transplant patient Adeola Olukayode. 36 year old Ade is a member of his church choir based in Hemel Hempstead. In 2014, Ade reached the bootcamp stage at Time2Shine, a Gospel version of X Factor.

To help us help you, we've created a Survey page on the website [www.westlondonkpa.org/surveys](http://www.westlondonkpa.org/surveys). These surveys have been created so we can get to know more about our readership. This way, we can tailor our services to best suit your needs. You can fill these in anonymously if you prefer and there are no obligations or catches!

**You could win one of these fantastic prizes in our World Kidney Day Raffle**

**1st Prize: £250**

**2nd Prize: £50 Bill's Restaurant Voucher**

**3rd Prize: £50 Boden's Gift Voucher**

**4th Prize: The House salon Gift Voucher for Cut and Blow Dry worth £49**

**5th Prize: TalkSport "Hawksbee & Jacobs" radio show experience – plus more prizes**

**Contact us: [mailbox@westlondonkpa.org](mailto:mailbox@westlondonkpa.org)  
Or visit [www.westlondonkpa.org](http://www.westlondonkpa.org)**

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