



Actively involving West London in
renal health issues and care

Registered Charity 275771

The West London Kidney Patients' Association Newsletter

September 2016

Hello everyone - I hope you have all had a fantastic summer and enjoyed the great weather that (eventually!) came our way. Summer brought with it an exciting list of events; the Euro's, Wimbledon, the Olympics and of course currently the Paralympics. We also had the British Transplant Games which this year took place in Liverpool - you can read all about it in this issue along with details of various day trips that we arranged for some of our patients. So all in all a busy Summer – especially for all of our helpers enabling these, and the many other activities we get involved in, to happen. The hard work continues as we move into the Autumn as we have a range of events for the coming months: a patient EXPO at the end of September, our AGM in October and all the usual festive season activities as well. We are always looking for more patients to come along and get involved or support us at these events. The AGM, in particular, has had a poor turnout so it would be great to see some of those patients who have attended our days out, the transplant games or any other events where we offer support, coming along to the next AGM in October (full details in this issue).



Days out

A slightly less strenuous activity – but one we are equally proud to support were this summer's seaside day trips. These are organised by the KPA and mainly focus on giving patients and their carers/families a day away. The day trips were spread over a few weekends and went to Eastbourne, Bournemouth and Brighton. For two of the outings the day trippers enjoyed a stunning aerobatic display as the visits coincided with the local air shows. In addition to walks along the piers and fish and chips and ice-creams some of the more adventurous patients also tried out Zip wire rides and also the new 530 foot British Airways Eye observation tower. A fantastic time was had by all – and a heartfelt thanks must go to Penne Sawford and Chetan Joshi for all their help in organising and running these.

AGM and EXPO

We did mention both the Patients EXPO and our Annual General Meeting in our last edition. However, with the dates for both these events now approaching we thought it would be worth a timely reminder for you to put the dates in your diaries so that you can attend.

Our AGM this year is on Wednesday 19th October. It kicks off at 6.30pm in the W12 Conference Centre, adjacent to the Renal building at Hammersmith Hospital. This is a real chance for us to hear from our members – So please come and join us! It is important for us as a review of our activity for the year and to look forward and plan focus and support for the forthcoming year. It also gives the opportunity to provide members with an update on the accounts and our overall financial position. This year will be a particularly interesting financial review so I really would encourage members to come along and hear about the latest developments.



In addition to providing updates we are joined by speakers who give engaging and insightful presentations related to their work. This year Dr Jeremy Levy will be giving his take on the developments and changes in Dialysis and Dr Frank Dor will talk about Live kidney donation and more specifically about laparoscopic donor nephrectomy - **We look forward to seeing you on the 19th October.**

We also have the Patient **EXPO 2016**. Here you can get the latest information and assistance on all things kidney related. No matter what stage of the journey you are with the disease we are sure that there will be something at the **EXPO** that will be of interest to you.

The EXPO has a mixture of stands, information booths, seminars and talks and is a fantastic source of information for all patients, carers and their families. There also will be a range of staff and support teams in attendance who will be able to help with any questions or queries you may have. Your KPA has representation at the EXPO so if you are planning on attending please do make sure you come along to our stand and say hello! As per the poster on this page, the EXPO is on the Wednesday **28th September @ 1pm** – again in the **W12 Conference Centre** next to the Renal building at Hammersmith Hospital. We look forward to saying hello to you on the day.

Transplant Sport Review

Whilst TeamGB were running rampant at the Olympics in Rio this summer the Hammersmith Team were enjoying equal success in the Rio of the North – Liverpool!

The team had a good turn out again this year with a team of 10 who won 10 medals! The KPA sponsored the team alongside support from the BKPA and also funds raised by the athletes themselves. Held over the course of a balmy weekend at the end of July the games aim is to encourage all transplant recipients to get active and be healthy whilst promoting organ donation. The games are for all ages and abilities with over 20 different events. These are pretty varied and this year the ones the team participated in included Archery, Basketball, 5 a side football, long jump, 200 metres and darts.



In addition to the activities it was a weekend of great spirits and socialising which was rounded off with a superb gala dinner where the team celebrated the medal haul with additional sporty moves on the dancefloor!

If anyone would like to become part of the Hammersmith transplant team please send an email to: sport@westlondonkpa.org



Medical Corner

We have a regular diet corner... We have featured our research team... hopefully the following will be the start of a series of articles taking more of a layman's approach to some of the medical conditions we face as explained by some of our much admired medical staff. The following on Pancreas Transplants is by Anand Muthusamy – one of the lead consultants at Hammersmith.

What is pancreas transplantation?

Pancreas transplantation is a major surgical procedure involving transplanting the whole of a healthy pancreas gland with its attached segment of bowel from a deceased donor, aimed at treating carefully selected patients with advanced complications relating to diabetes.

Diabetes is broadly divided into two types:

<i>Type 1</i>	<i>Type 2</i>
where your own pancreas does not make enough insulin, leading to high blood sugars; this is less common and typically seen in children and young adults	the more commonly seen type of diabetes where your body is unable to make use of the appropriate amount of insulin made by your pancreas; this type of diabetes is increasing rapidly across the world, typically seen in adults and is associated with weight gain.

What does the pancreas transplant do?

A functioning pancreas transplant responds to your blood glucose levels by producing an appropriate level of insulin to maintain blood glucose levels within normal range. This means freedom from insulin treatment on a day to day basis. However, the main advantage is increased life expectancy and longer kidney transplant function.

Who is a pancreas transplant for?

The benefit of pancreas transplantation is greatest in people with Type 1 diabetes as the transplanted pancreas resolves the issue of insulin deficit. However, there are a small proportion of people with Type 2 diabetes who are typically slim, needing to have insulin treatment and have advanced organ damage due to diabetes, who could be assessed for their suitability for pancreas transplantation.

What types of pancreas transplant are there?

If you have kidney damage due to diabetes, you would have either a dual transplant with a kidney (**simultaneous pancreas kidney transplantation SPK**), or have the pancreas transplant performed as a separate procedure following a successful kidney transplant; this procedure is called a **pancreas after kidney transplant (PAK)**. A select few diabetics with life threatening complications due to their inability to respond to or treat low blood sugars (hypoglycaemia) would be offered a **pancreas transplant alone (PTA)** to manage their blood sugar control.

Why don't we perform pancreas transplant on everyone with diabetes?

Pancreas transplantation is a major surgical procedure with considerable risk of complications; hence if you are considered to be too sick to undergo the transplant procedure, you may not be offered a pancreas transplant. On the other hand, pancreas transplantation would not be suitable for most people with Type 2 diabetes as they are likely to make adequate amount of insulin which is not utilised by their body. To know more about the risks and potential benefits, contact your kidney doctor or request an appointment with the pancreas transplant team.

Pancreas transplantation at West London

The Imperial College Renal Transplant Centre is one of seven designated pancreas transplant centres in the United Kingdom. We are one of the largest specialist centres in kidney disease in the country and have performed over 100 pancreas transplants since 2005; to know more about pancreas transplantation and what we do, please visit

<http://www.odt.nhs.uk/information-for-patients/pancreas/>

For updated transplant outcomes, please visit

http://www.odt.nhs.uk/pdf/organ_specific_report_pancreas_2014.pdf

Getting results ... sooner!

Having sat and “people watched” myself in our clinic waiting areas, it has become more and more evident that a lot of our members are using smart phones and other tech devices. Given that we are always happy to see new tools or services that use this technology to improve patient welfare, we are pleased to inform you that soon all Imperial Trust patients will be able to access their medical information through a new web and app based service called **Patient Knows Best (PKB)**.

PKB is a trust wide initiative that allows patients and carers access to their medical information. This will eventually include all details on consultations, scans and X-ray information, blood results and other lab information as well as full details of all forthcoming appointments via a diary/ calendar system. The system is linked to the trust’s Cerner computer information system so is also constantly updated. There are also links to North West London Hospitals result systems e.g. Ealing, Northwick Park and Central Middlesex. We hope this will avoid duplication of tests by different care providers.



The best thing is that there will be no need to wait for your next clinic appointment or dialysis session to know what the results of your last test were – you will be able to log in and get your results yourself as soon as they are published.

Some members of the committee are currently testing the platform – and we are pleased to report that following a clinic appointment last Monday morning the results of the bloods taken in clinic were available that afternoon.

In addition to be able to get your results quicker and in between appointments other important benefits of this new service is that you will be able to get access to your information and you can also share the information with others – eg your GP etc. Even if you don’t have access to a computer or have a personal email address you can nominate a family member e.g. son/daughter, carer or friend to receive the information on your behalf.

Of course with any new technology or service there always has to be a health warning. When publishing results and information the system does provide an explanation of the area measured and a “normal” reading. The key thing patients will need to remember is that all patients are individual – and likewise so will their results be. So when reviewing the information all patients will have to be mindful that their individual results are exactly that - individual. So don’t panic for example if your creatinine reading appears higher than average or “normal” levels strangely enough all Kidney patients should expect that at some of the delightful journey of the disease! So far we have trialled the program in dialysis and transplant clinics but we hope to rollout to all renal clinics and satellites in the near future and look forward to bringing you more details soon.

Making this a conversation...

As we mentioned in our last newsletter we have a new brand image that is rolling out across all of the messages, materials and general correspondence that you receive from us. In addition, to make it easier for you to communicate with your kidney patients’ association, you can now contact us through area or interest specific email addresses (see the full list below). Please do use our emails – it would be great to hear more from you – no matter what the subject!

Info@westlondonkpa.org	General information or requests
Support@westlondonkpa.org	For specific support or help queries
Editor@westlondonkpa.org	For input or commentary on newsletter articles
Sport@westlondonkpa.org	To register or request information regarding Transplant Sport activity
Join@westlondonkpa.org	All patients are usually automatically enrolled – if not this email is used to enrol
Chair@westlondonkpa.org	To get involved, join the committee or for general contact please email the Chair
Secretary@westlondonkpa.org	Address admin queries or requests for funding/support to this email
Treasurer@westlondonkpa.org	To make donations or for any general financial queries

Diet Corner – September 2016

Ask a Dietitian

'What take-away and fast food meals are OK for me to eat as a treat once in a while?'

Take-Aways can be easy and tasty! With a little thinking about your choices you can enjoy a fast food meal while watching your intake of salt, fluid, potassium and phosphate. Here are some ideas:

- 🍷 If you know you will be having a take-away or meal out, be careful beforehand/afterwards to allow foods you may not normally have, e.g. cut down on high potassium/phosphate foods and fluids to allow yourself more choice in your meal. Have a look at the menu beforehand so you can think about the best options.
- 🍷 If prescribed phosphate binders e.g. Sevelamer, make sure to bring them along to take when you eat.
- 🍷 When choosing what to have, try to balance the potassium content by not picking too many high potassium foods; e.g. if you fancy chips, avoid having tomato or mushrooms. Try to choose fresh meats/fish e.g. chicken, beef, tuna instead of processed foods like bacon/salami which can contain phosphate additives. To help manage your fluid intake, stick to a child-sized beverage.
- 🍷 Salt is often added to chips, salads, and meat during or after cooking. When you are ordering, ask if your food can be cooked or served without salt and for potentially salty sauces to be served on the side.
- 🍷 You may wish to save left-overs for another time. It is important to remember food safety to prevent food poisoning, especially if you are taking immunosuppressant medicines after a kidney transplant. Store covered leftovers in a fridge as soon as possible once cooled for up to two days (24 hours for cooked rice). Reheat thoroughly until piping hot throughout. Don't reheat the food more than once.

Tasty Options When Ordering!!!

Fast Food <ul style="list-style-type: none"><input type="checkbox"/> Plain beef, chicken, lamb, veggie burger or kebab<input type="checkbox"/> Fish in batter/breadcrumbs<input type="checkbox"/> Small side salad of lettuce, cucumber, tomato & onion or coleslaw<input type="checkbox"/> Small serving of chips/onion rings with vinegar/mayonnaise instead of ketchup/salt	Indian <ul style="list-style-type: none"><input type="checkbox"/> Drier curries e.g. biryani, shashlik, tandoori<input type="checkbox"/> Plain rice, naan bread, chapatti or roti instead of pilau/seasoned rice, curried potato or peshwari/keema naan<input type="checkbox"/> Small side salad of lettuce, cucumber tomato & onion.<input type="checkbox"/> Chilli and spices for flavour
Chinese <ul style="list-style-type: none"><input type="checkbox"/> Stir-fried beef, pork, chicken or tofu in sweet & sour/lemon sauce<input type="checkbox"/> Small side of stir fried vegetables e.g. carrot, broccoli, onion with plain rice or noodles<input type="checkbox"/> Avoid adding soy sauce/fish sauce	Pizza <ul style="list-style-type: none"><input type="checkbox"/> Suitable toppings include: chicken, beef, tuna (instead of salami, bacon, ham or anchovies); peppers, sweetcorn, onion, pineapple (instead of olives or mushrooms)<input type="checkbox"/> Avoid extra cheese or tomato<input type="checkbox"/> Use black pepper, herbs, chilli for flavour

Recipe – Crunchy Noodle Stir-Fry

Try this quick, low salt version of a classic Chinese dish if you want to make your own!

Ingredients (serves 2)

- 1 garlic clove, chopped finely
- 200g strips of lean beef/chicken/pork or cubed tofu
- 300g sliced vegetables of your choice e.g. broccoli, carrot, baby sweet corn, onion, beansprouts
- 2 tbsp. vegetable oil
- 2 cups cooked noodles
- 2 tablespoons reduced-sodium soy sauce
- Sliced red chilli and finely shredded spring onion



1. Heat the oil in a frying pan or wok and stir-fry the beef/chicken/pork/tofu with the garlic. Add the vegetables and stir-fry until the meat/tofu and vegetables are cooked.
 2. Remove from pan and set aside. In same pan add the cooked noodles and soy sauce. Fry on a high heat until golden and crispy.
- Mix with the meat/tofu and vegetables. Garnish with sliced red chilli and finely shredded spring onion.