



Actively involving West London in  
renal health issues and care

Registered Charity 275771

## The West London Kidney Patients' Association Newsletter September 2017

**Hello from your temporary editors for this edition of the newsletter.**

The nights are drawing in and we hope you've had a wonderful summer, maybe you went on one of the day trips, attended the Transplant Games or enjoyed our Summer BBQ. Reviews and Photo's can be seen below.

*We would like to offer our congratulations to our Patron, Vassilios Papalois on his appointment as Editor of E-Journal Association of Surgeons of Great Britain and Ireland (ASGBI).*

*Please see link [http://www.publications.asgbi.org/jasgbi\\_14\\_07\\_17/index.html](http://www.publications.asgbi.org/jasgbi_14_07_17/index.html)*

We have a new addition to our Newsletter, below you will see our first article from the Renal Pharmacists.

### **Notification of West London Kidney Patients' Association AGM**

Our Annual General Meeting this year will be on 19<sup>th</sup> October 2017.

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### **Christmas Party for Sunday 10<sup>th</sup> December 2017**

For those of you who remember our past Christmas parties, there is a change of venue.

Due to health and safety rules plus lack of space in the hospital we have looked further afield, not too far though, just to **The Pavilion Pub, North Pole Road, Shepherds Bush, W12 0HQ**. It's not far from Hammersmith Hospital, end of Du Cane Road turn left on to Wood Lane and up to the traffic lights on the right.

We have negotiated the use of the room on the side for our Christmas party with a Christmas buffet lunch with background music. Please note there are 3 steps to enter the building, please take that into consideration when booking. In previous years we have welcomed your contribution, food wise but again due to health and safety we have to use the menu provided.

Ticket price: £5 per head, which is also your voucher for your first drink.

Refunds are not available. Free Parking is provided

The date to put in your diaries is **Sunday, 10<sup>th</sup> December 2017, from 12 midday through to 6pm.**

We look forward to hearing from you, for booking your place please contact

Penne: [chair@westlondonkpa.org.uk](mailto:chair@westlondonkpa.org.uk) for further details



*If you have a change of address or no longer to receive the newsletter please email [chair@westlondonkpa.org](mailto:chair@westlondonkpa.org)*

## **Christmas Card sales**

I can hear you say, "Christmas Cards already".

**Yes!** due to printing and timing restriction we have to mention it now, but hopefully one of the dates mentioned below will be perfect for you, either as a volunteer or as someone who sends cards abroad.

Enclosed within this newsletter is our ordering form, those who are regulars know how to order, for our newbies we hope everything is self-explanatory.

If you feel you can offer a few hours to help us in Hammersmith Hospital foyer, the Renal Centre or Charing Cross Hospital opposite the café on the first floor. Please contact Sharman on 07749865381. The dates for Hammersmith Hospital & the Renal centre are: Mon 30<sup>th</sup> Oct, Thur 2<sup>nd</sup>, Mon 6<sup>th</sup>, 13<sup>th</sup>, Fri 17<sup>th</sup> & Wed 29<sup>th</sup> November. The dates for Charing Cross were not available at time of going print.

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## **CKD SHARED CARE PATHWAY PROJECT TEAM**

For the last 2 years a project team consisting of a group of doctors, nurse and a dietician, have been working with our local CCGs and GPs to develop a shared care pathway for patients with stable kidney disease to be cared for in the community. The aim of the project has been to provide quality CKD care, closer to home and supported by an education programme for patients and General Practice staff. By doing this we hope to slow deterioration of kidney function in patients with chronic kidney disease as well as reduce the cardiovascular complications associated with this disorder. Furthermore it is expected that the nephrology hospital service will be able to offer a better service to those patients with deteriorating kidney function and particularly for those who are likely to require end stage renal failure therapy. The project has been a great success, even being a runner up for the ICHT Chairman's award 2017. The project would benefit from an increased level of patient input.

We are therefore looking for volunteers to join the project team. Please contact Helen Watts, Lead nurse practitioner on [helenwatts1@nhs.net](mailto:helenwatts1@nhs.net) with your contact details and she will call you to discuss the project details and type and level of commitment required.

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## **Transplant Games 2017 was held in Lanarkshire, Scotland**



**WOW!!** What a year for Team Hammersmith, best ever from the array of medals won. One Gold, 6 Silver and 11 Bronze making a total of 18, with 7 competitors and 7 supporters it was a bonanza. After 4 years of going to the games, coming home empty handed, one of our competitors Won a Gold, 2 Silver and a Bronze, that's called a full house.

The sports that are available to participate in are so numerous, here is a selection: Archery, Badminton, Bowls, Cycling, Darts, Fishing, Golf, Snooker, Squash, Swimming, Table Tennis, Tennis,

Ten Pin Bowling, Track and Field and Volley Ball, why not join us next year.

Laura, came to the transplant games as a supporter, she has written of her experience at the games, this was her and her partners first visit to the games. "When my partner told me about the games, I wasn't particularly enthusiastic. I'd never heard of it before, and I'm not the most athletic person, so didn't think it would be my cup of tea. Nonetheless, my partner wanted me there to support him so I agreed to go. I couldn't be more pleased I did! The atmosphere was like no other. We felt instantly welcomed and part of not only a team but a wonderful community. I've never seen my partner look so comfortable. We were surrounded by people who understood, from the perspective of a recipient and of a loved one. It was a chance to ask questions and talk freely about subjects that people don't often talk about. And it was so much fun! There were so many sporting events that I'd never been interested in before, that were suddenly exciting and fun to me because of the spirit involved. Next year I plan on taking part in an event and my partner is going to try some new sports. Thank you, Team Hammersmith!"

If you are interested in joining the team for the 2018 Games which will be held in Birmingham please contact the Hammersmith Team Manager – Dino on [Teamhammersmith@gmail.com](mailto:Teamhammersmith@gmail.com)

## **Renal Pharmacy News**

### **Home delivery medicines**

The home delivery service is now provided by **Lloyds Pharmacy Clinical Homecare (LPCH)**.

#### **Please remember:**

- You should always keep 1 month of medications supply at home.
- You must request a homecare prescription when you come to your clinic appointment.
- Ensure the duration of the prescription keeps you going until your following clinic appointment.

**The prescriptions are NOT automatically renewed – you must ask during your clinic appointment.**

If you are handed a prescription in at clinic and have not heard from Lloyds to organise your delivery, you can call them on 0345 263 6123 choose option 1 then option 4.

### **Buying medicines over the counter**

You must not take any medicines or supplements that you can buy over the counter.

These include:

- Herbal
- Homeopathic
- Natural
- Ayurvedic
- Chinese herbs
- Other over the counter medicines and supplements that you can buy in pharmacies and health food shops.

The only medicine we recommend you buy over the counter is paracetamol.

Some particular examples of medicines that you can buy over the counter that you should not take are:

- Anti-inflammatory medicines such as ibuprofen, Nurofen, diclofenac or Voltarol, not even as an ointment or gel.
- St Johns Wort which is a popular herbal remedy that you can buy but should not be used with immunosuppressants and some other medicines because of interactions.

There are many other examples so it is crucial that any medicines you want to take are carefully checked.

### **What should I do if I forget to take a dose of my immunosuppression?**

We get asked a lot about what you should do if you forget to take one of your doses of immunosuppression or if you realise that you are going to take it late.

If you take your immunosuppression medication twice a day (every 12 hours):

- This includes Adoport, Prograf, Ciclosporin, Mycophenolate
- Take 6 hours as your midpoint.
- If you're up to 6 hours late then take the dose when you remember and still take the next dose at your normal time.
- If you are more than 6 hours late then you must miss that dose and take the next dose at your normal time.

If you take your immunosuppression medication once a day:

- This includes Advagraf, Azathioprine, Sirolimus
- Take 12 hours as your midpoint.
- If you're up to 12 hours late then take the dose when you remember and still take the next dose at your normal time.
- If you are more than 12 hours late then you must miss that dose and take the next dose at your normal time.

### **Travel advice**

Before you take any trips abroad, ensure you get very good travel advice well in advance of your travel.

Unfortunately, we do not run a travel clinic at the hospital but your GP surgery will or you can go to an independent travel clinic. You will need to take with you a clear itinerary of where you are intending to travel to. The travel clinic will:

- Tell you if you need any travel vaccinations (you must not have any live vaccinations if you are taking immunosuppression medication)
- Tell you if you need to take malaria prophylaxis tablets
- Give you general travel advice.

The travel clinic may not be aware of interactions or dose adjustments with your medications so discuss this with the renal clinic well before your date of travel. It can be difficult to manage the times of your medication when you are traveling across time zones. Please ask the clinic team for advice before you travel.

### **Pharmacy advice**

Please ask to speak to a member of the renal pharmacy team if you have any questions or concerns about your medicines. There is usually a pharmacist in clinic Tuesday to Friday (from October we are hoping to extend this to Monday's too) and you can just pop in, you do not need to make an appointment. If the pharmacist is not available, you can ask one of the nurses to contact us and we can help you.

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## **Organ Donation Week 2017**



As usual West London KPA promoted Organ Donation last week. We had stands at Hammersmith and Charing Cross Hospitals.

If you have signed the NHS organ donor register it is still very important that you have the conversation with your family so that they know your wishes. Talking about organ donation makes it easier for families to decide to donate a relative's organs. More and more renal patients are benefitting from live donation from a family member or friend as well as altruistic donation. For more information visit NHSBT's website. To register visit: [organdonation.nhs.uk](http://organdonation.nhs.uk) or call 0300 123 23 23

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