



Actively involving West London in renal health issues and care

Registered Charity 275771

The West London Kidney Patients' Association Newsletter August 2017

Hello everyone – Here we are again – Wimbledon has come and gone, the last of the school exams seem to have finished and we are about to start on the long-awaited summer break. We have been spoilt with the weather of late as well.

So, as we all start to look forward to the full throes of summer it is time for our usual – almost traditional - word of warning.

For most mere mortals getting out in the sun, whether here or sunnier climes abroad, is all fine. However, for those of us with our special renal conditions – either Transplant or Dialysis patients - we need to be extra careful in the sun.



So, whilst getting a boost of vitamin D is good for the soul, and also has positive effects on the skin tone, we all need to take precautions and ensure that we protect ourselves from the sun's harmful rays. The Australians have their very nice phrase for it which I am sure you have seen in our previous editions - you need to make sure you slip, slop, slap. Slip on a shirt, slop on the sun cream and slap on a hat!

That rule will especially apply if we are blessed with good weather for our **big event** for the summer. As mentioned in our last edition please, please make sure you keep **SUNDAY 13th AUGUST** free for our **FREE ADMISSION SUMMER BARBEQUE**. It will be a great day so we want as many of you to come along and join us and have a fun time. We hope to see you there!

Our Summer event

As you will see from the poster on the pack of this edition's Diet Sheet we are really excited to be hosting a Summer Barbeque Fundraiser. The Barbecue is on **Sunday 13th August** at **Wasps Rugby Club, Twyford Avenue Sports Ground, Twyford Avenue, Acton, W3 9QA**.

In addition to the usual fayre of Burgers etc we will also have stalls with Indian Street food as well as others with Cakes and sweets and much more. There will also be a great array of entertainment and talent on display including singer Heidi McCaffrey, Bollywood dancing, a Steel band and Stardust Arts Carnival Group. There will also be a wide range of other stalls including tombola's and face painting.

Of course, as with all of our events, in addition to offering all of our patient members and their carers an opportunity for a great afternoon out we will also be using it to raise funds and awareness of kidney disease.

Please do mark the date in your diary and come along to support YOUR Kidney patient association – we look forward to seeing you there



If you have a change of address or no longer wish to receive the Newsletter please email chair@westlondonkpa.org

Improving patient experience at Northwick Park & Brent Renal units

We are always pleased to learn about improvements in the Trust's renal offering that are of benefit to our patients. More importantly we also appreciate the efforts of staff who often have to work above and beyond their everyday duties to deliver those.

One such improvement is an extension to Claire Edwards and Elizabeth Dalby's roles to allow them to become non-medical prescribers (NMP).

Claire is Head Nurse at Northwick Park's Renal Centre, Elizabeth is Head Nurse at Brent Renal Centre.

Claire and Elizabeth originally undertook a 'non-medical authorisation of blood products' course run by senior blood transfusion nurse practitioners 3 years ago. Having been NMP's for several years now they recognised a need to further extend the role as patients were often waiting for a prescription to be signed by a doctor when they attended for clinics which resulted in delayed transfusion.

As the Trust had no policy for this specific area they developed a protocol and policy to reduce the delays. This was undertaken in collaboration with the blood transfusion consultant and nurse practitioner but took this 3-year hiatus to get approval by which time they chose to re-sit the course spending another 5 days at the UK BT laboratory in Bristol. The course was attended by nurses from many specialities and well worth the additional time spent as they got to review the full – sometimes baffling – scientific overview of how blood is processed from donation through to patient ready state.

They are the Trust's first nurses to be approved to *authorise* blood and blood products (not allowed to call it *prescribe* as it is not a drug!). In addition to all of the training they also needed a consultant colleague to take on the role of designated medical practitioner, the person responsible for signing off our competencies and ensure they remained safe to practice. Neill Duncan agreed very generously to take on this responsibility and Claire and Elizabeth were finally signed off in April authorising their very first unit of blood the very next day!

The aim now is to monitor the time required for patients needing blood to receiving a transfusion – this would previously have been delayed until a doctor attended the units. In addition, they plan to audit the number of units requested when the decision to transfuse is made as traditionally this was always 2 but they believe often 1 is sufficient.

We would like to wish Claire and Elizabeth every success in their new roles and our heartfelt thanks for their ongoing dedication in helping to make their renal patients' lives easier.

Need a longer break



If any of our Dialysis patients have a hankering for a break that is a bit longer than our day trips St Anne's Holiday Dialysis can offer something a little more appropriate. St Anne's is a specialist facility that offers holiday dialysis, with onsite self-catering accommodation also available, at Emsworth in Hampshire on the picturesque south coast.

The purpose designed dialysis unit is situated just a few steps from the house, has three haemodialysis stations where patients are looked after by a Nephrology nurse & team. There is a wide-screen TV in the unit and patients on dialysis have views over the garden. Patients can relax here in safe hands.



St Anne's Holiday Dialysis Centre is open to dialysis patients of the West London Hospitals Holiday Trust free of charge and for ONE other partner or next of kin and their own children under 12 years. There is a nominal charge for additional guests, transplant patients and for patients from all other hospitals who are most welcome too. Patients also have the option to book their own accommodation elsewhere, but take their dialysis sessions at St Anne's Holiday Dialysis Centre.

Can you help with fund raising?

We are grateful to everyone for all of their fundraising efforts and activities. As with all charities we rely on the efforts of our all of our fundraisers and givers to ensure we are able to continue our good works well into the future. Of course, there are many different ways to achieve this fundraising. As per previous issues we thought you would like to hear about a couple of examples.



Our collection pots are a vital part of this activity. We have traditionally relied on having these collection pots dotted around each of the main Imperial Hospitals – or satellite units. Our challenge today is that it has become more difficult to be able to find authorised positions to place these. We have therefore had to find other locations to collect funds. One such location is The BMI Coffee bar at Clementine Churchill Hospital. We are fortunate that Sue, one of the staff that runs the bar, is the wife of Eric Kapora, one of our dialysis patients at Northwick Park.

We also have collection boxes at other locations. Nilu is a patient at the Hammersmith transplant clinic. Her family have several shops including the “8 til late” store in Lampton Road near Hounslow Central and have kindly let us have several collection boxes at their tills.



Given the proximity to the nearby tube station these are an excellent source of funds for us with the boxes having to be emptied every few weeks. Of course, like most collection boxes there are a lot of copper coins – less silver and the occasional £1 or £2 coins, but all mount up very quickly.

Over the last year or so the boxes in these locations alone have raised over £820. One of the great challenges for us is getting the sheer weight of the coins to the bank!

All of the help and assistance from all of our supporters is very much appreciated. If you are able to help and can volunteer to assist with fundraising please do let us know. Also, if you know of a shop, café or any other location that would be good for one of our collections boxes, again please just email us at: secretary@westlondonkpa.org

Transplant Sport



By the time you read this the British Transplant Games should be taking place. This year over 750 inspiring athletes from across the UK, each of whom has received a lifesaving organ transplant, will descend on North Lanarkshire along with around 2,000 supporters to take part in 23 different sporting activities over the 4 day event. Athletes are aged between 3 and 81 and will compete in competitions including archery, athletics, golf, squash, snooker, tennis and swimming.

The Games, organised by the charity Transplant Sport, aim to demonstrate the benefits of transplantation, encouraging transplant patients to regain fitness, whilst increasing public awareness of the need for more people to sign on the NHS Organ Donation Register, as well as the Anthony Nolan Bone Marrow Register, and discuss their wishes now with their families.



Our Hammersmith team will have 8 transplant athletes - 3 of whom are double transplantees, having received a kidney & pancreas - all competing in various events. We will also have 7 supporters who will be encouraging the team in their events. We would like to wish all of those participating the very best of luck and hope that they enjoy all that the event has to offer. Hopefully we will be able to bring you some news of their medal winning efforts in the next edition.

An Important change for one of our friends

It seems that we're not the only people to be changing our appearance. We hope you have noticed and approve of the change we have made to our logo and overall branding over the last few months. We believe it has certainly helped us to get noticed more amongst our members and on the crowded notice boards in the hospital corridors and waiting rooms!

Our friends at the British Kidney Patient Association (BKPA) have the same challenges and obvious ambition – albeit on an even larger, national scale.

The BKPA has been helping the British renal community for over 40 years. As with all Charities and support organisations one of the key things the BKPA needed to do was ensure that they are recognised and what they do is clearly understood.



To ensure that this was the case the BKPA decided to talk to a few of the people they represented and supported. They talked to nearly 1000 patients, family members and health professionals over the last year. As a result of these discussions the feedback was clear; there was confusion in the kidney community about all the various charities and what they did, and that their old name wasn't working as well as it could have and needed to change.

As a result of having listened to these comments and using everyone's views and ideas the BKPA has renamed the charity as Kidney Care UK in order to help reach and support even more kidney patients and their families in the future. The newly designed logo below is the result of this hard work and you will have started to see this appearing on various pieces of literature and communication over the last few weeks.

Whilst the name and logo is changing the commitment from the organisation to continue to offer all the support services they provide now, as well as developing new ways of helping, continuing to improve health and care services and campaigning for change.

Over the next few months you will see the new name and new look as Kidney Care UK continues to raise awareness of the change amongst patients and supporters.

This Year's Day Trips

Although we are only part way through the summer we have been very busy already with our day trips. By the time you receive this there will only be a few remaining opportunities to take advantage of our supported days out to the great British Seaside. If you do want to take part have a look at the trip destinations and dates shown here.

DATE	DESTINATION	DEPARTING FROM	TIMES
SUNDAY 25 th JUNE	WINDSOR	CENTRAL MIDDLESEX HOSPITAL(BRENT UNIT) ACTON LANE. LONDON NW10 7NS	09:00 Departure 19:00 Return*
SUN 9 th JULY	BRIGHTON	HAMMERSMITH HOSPITAL, DU CANE ROAD, LONDON W12 0HS	08:00 Departure 19:00 Return*
SUN 23 rd JULY	SOUTHEND	EALING HOSPITAL UXBRIDGE ROAD, SOUTHALL UB1 3HW	08:00 Departure 19:00 Return*
SUN 6 th AUGUST	CLACTON-ON-SEA	NORTHWICK PARK HOSPITAL, WATFORD ROAD, HARROW HA1 3UJ	08:00 Departure 19:00 Return*
SUN 20 th AUGUST	EASTBOURNE	CENTRAL MIDDLESEX HOSPITAL(BRENT UNIT) ACTON LANE. LONDON NW10 7NS	08:00 Departure 19:00 Return*
SUN 27 th AUGUST	MARGATE	EALING HOSPITAL UXBRIDGE ROAD, SOUTHALL UB1 3HW	08:00 Departure 19:00 Return*
SUNDAY 3 rd SEPTEMBER	BOURNEMOUTH	NORTHWICK PARK HOSPITAL, WATFORD ROAD, HARROW HA1 3UJ	08:00 Departure 19:00 Return*

Tickets are only £10

available from Penne Sawford. Tel: 07983 406025 or chair@westlondonkpa.org

Given last year's success and the days already delivered this year the events are very popular so please do make sure you book as soon as possible to avoid disappointment. For full details look out for the posters in your unit or contact Penne Sawford on 07983 406025 / Chair@westlondonkpa.org

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