



Actively involving West London in
renal health issues and care

Registered Charity 275771

The West London Kidney Patients' Association Newsletter

May 2018

Well it seems like it was a very long winter but at long last we seem to be edging into Spring – and with it some warmer weather and hopefully sunshine. Time for all of us to dust off the winter cobwebs and get busy with all those chores we were putting off until it got warmer, drier or even just that bit nicer outside. The WLKPA is no different – although from what you will see from all of the updates here for forthcoming trips and other activities we don't really let up during the cold dark months of winter either. Those fun activities take a lot of organising! As you will see in this newsletter there is hopefully a lot for everyone to get involved in this year.

However before getting into the fun aspects of what we do we would like to draw your attention to the most important section of this newsletter – and the accompanying form. Please take a couple of minutes to complete the form and return to us in the enclosed envelope so that we can keep in touch – we would hate to lose contact with you!

Having done that we hope you enjoy reading the rest of the updates and also about our activities and plans for the rest of this year. We hope you will be able to join us in one or two of them. Either way have a great time banishing those long winter blues - we look forward to speaking with you again soon.

WANT TO KEEP HEARING FROM US? – YOU NEED TO LET US KNOW NOW!

The reason you are able to read this, and all of our other newsletters and communications is because you previously agreed to receive this type of information from us. We are really glad that you did, as keeping in touch with renal patients across all the various clinics and units in West London is vital for us.

As of the 25th May 2018 there is new legislation called the General Data Protection Regulations. In order to make sure that we are able to continue to communicate with you and keep you up to date with all of the work we are doing – days trips, diet information, hospital news etc you need to let us know that this is OK with you. You do that by completing the form sent with this newsletter and sending it back to us in the self-addressed envelope provided.

If you don't let us know this could be the last newsletter you receive!!

World Kidney Day

We had yet another great turnout for World Kidney Day this year. As with every year the organisers decide on a theme for the year – this year's theme was Kidney disease and women's health.



As usual we had a range of different activities to support the event – with WLKPA presence at Hammersmith, Charing Cross and also at a staff Dialysis academy. One of our dialysis patients from Northwick Park, Abdul Khares, raised awareness and funds for us at Stanmore College again this year. As always, we would like to thank all of our volunteers who gave us so much help both before and during the various events.



We also had our usual raffle which was well supported – see below also for detail of the winners.

Many thanks to all the people who continue to support us by buying raffle/draw tickets through the post and from our volunteers on the day.



WLKPA World Kidney Day Raffle Prize Winners			
1st Prize	07466 Karen Dwyer	2nd Prize	03178 John Adamson
3rd Prize	11471 L Lee	4th Prize	06159 Anad Salman
5th Prize	01636 Pat Hawkins	6th Prize	08490 P McAuliffe

Day trips 2018

We are pleased to announce that we will once again be running our programme of day trip activity this year. Each year seems to keep on getting better and so please do make sure you book early to avoid disappointment.

Trip destinations and dates are shown on our posters around each of the units and here. For full details look out for the information in your unit or contact **Penne** as per below, or book online:

Mobile 07538 224 156

Email: trips@westlondonkpa.org

**To book tickets – online
www.westlondonkpa.org**



**Get your tickets
for this summer's day trips**

Date	Destination	Departing from	Ticket Price
1st July 2018	Woburn Safari Park	Ealing Hospital	£15 each
15th July 2018	Isle of Wight	Central Middlesex	£20 each
29th July 2018	Thorpe Park	Northwick Park Hospital	£15 each
19th Aug 2018	Eastbourne	Ealing Hospital	£12 each
2nd Sept 2018	Bournemouth	Northwick Park Hospital	£12 each

This year we are having a trial of cashless payments. Tickets can be purchased online from our website www.westlondonkpa.org. You can pay by Debit or Credit card or with Paypal.

TICKETS ARE ON SALE NOW!

Tickets are sold on a first come, first served basis. Each renal patient can bring up to five other guests (family and friends) Terms & Conditions do apply. Further details can be found on our website. If your chosen day trip is sold out, you will be put on a waiting list and we will inform you if any last minute seats do become available.

For all enquiries, please email trips@westlondonkpa.org or call **Penne** on 07538 224 156.

Sunday afternoon events and other dates for your diary

We recognise that not everyone will be able to make it onto the day trips away. Therefore, this year we will also be offering a few fun filled afternoons of entertainment. We have booked the function room at The Pavilion where we held our Christmas party last December for the afternoons of 3rd June, 24th June and 9th September and intend the activities to last from 12.00pm through to 6.00pm.

The actual afternoon's entertainment is still to be confirmed with early front runners being a "race night", Bingo, Karaoke and a Quiz. Please do make sure you mark those dates in your calendar and we will confirm all the finer details nearer the time.

If you want to be a record breaker.....

I am sure a few of you will recognise that line from the kids' tv programme! As you will have seen from reading this newsletter previously, we are always very pleased and proud of everything that we as patients, and the hospitals who take care of us, are able to achieve. In particular at the moment we are really pleased to have a record holder amongst our numbers.

"Mahesh Mehta – one of our WLKPA members - holds the Guinness World Record for the longest time on haemodialysis having been dialysing for over 43 years and counting. Whilst we initially thought how sad for him having over two thirds of his life on dialysis Mahesh and his family think quite the opposite. They think how great to have been on dialysis for 43 years and still be here enjoying full quality of life.



Mahesh had 2 failed kidney transplants (1 in 1979 and 1 in 1990), he was on home haemodialysis dialysis before and after the transplants. He chose to come in centre to us at Northwick Park in 2004 when he and his mother found home dialysis was becoming a burden for them both. He is a very interesting and humble man, who despite his disabilities including the sudden loss of his sight a few years ago, remains positive with a fantastic outlook on life."

Mahesh will be celebrating his achievement at Northwick Park dialysis unit. We would like to congratulate him, his family and all of the staff and carers across all of the units who have helped him along his momentous journey.

40 Years and still going...

Continuing on the theme of amazing longevity your wonderful KPA is celebrating 40 years of diligent work supporting patients this year. It is amazing how time flies! In that time whilst our name, logo and various committees and support teams have changed the core fundamental belief and ambition have remained the same. We exist to:

- Provide information and support to people with renal failure, their families and carers.
- Improve medical facilities
- Support national renal organisations
- Raise public awareness about renal issues

You can trace our history through the Charity Commission whose role is to manage and administer the role and functions of all UK Charities. A visit to their website shows that the Hammersmith Hospital Kidney Patient Association was first registered with them on 25th April 1978. With the mergers of St Mary's KPA and Charing Cross KPA this was amended to West London Kidney Patients' Association on 8th March 2011.

Prof David Kerr (some of you may recognise that familiar ward name) supported us as Patron and Hospital liaison until Prof Gordon Williams took on that responsibility in 2000. In 2006 our very own Elaine Clutterbuck took on that role until 2017.

Throughout the last 40 years all of the various committee members have driven the charity's aims and provided support for that through fundraising bike rides, fashion shows, bangrah dance and patient trips. Perhaps the largest venture in that period was where 44 patients and families went to Florida Disneyland, which took 2 years for the KPA to fundraise/organise! Given the efforts to manage our current annual day trips that must have been a herculean task!

Below you can see just a sample of the memories and events committed to film over the years. If you would like to see and hear more about what we have done over the years please join us at the hospital on Thursday 24th May between 10.00am and 3.00pm. You will be able to find us at the main hospital foyer and also the entrance to the renal unit.



St Anne's 2018 Sponsored Walk



The West London Hospitals Holiday Dialysis Trust is holding its 43rd Annual Sponsored Walk in Richmond Park on **Sunday 10th June**.

As in previous years the event is supported by Her Royal Highness Princess Alexandra who will be starting the walk at 9.30am. The walk is not a strenuous one. It is about 5 miles and all on level ground. The start point is East Sheen Gate.

Fuller details were recently posted so hopefully you will have received them already. Alongside additional information about the event there is also a sponsorship form.



We do hope you are able to support it. All funds raised goes to the West London Hospitals Holiday Dialysis Trust. This important, registered Charity enables renal patients and their family and friends to enjoy a self-catering holiday with dialysis at St Anne's in Emsworth Hampshire; For more details please visit www.stannesdialysis.co.uk

Transplant Games



Whilst on the subject of walking for good causes it would be remiss of us not to extend our usual invitation to join the team at the Transplant games. For the last few years we have had a really good turnout from Hammersmith and an equally impressive haul of medals. No this doesn't mean that you have to be a budding Victoria Pendleton or Mo Farah – far from it.

The games are for all patients at all levels of physical ability. The activities include archery, golf, 10 pin bowling, snooker and walking. So, something for everyone and it is also open to all ages!

The games this year are being held in Birmingham over 4 days from August 2nd – 5th. There are an expected 850 transplant patients taking part in over 25 events. So, what are you waiting for? Get yourself motivated and contact team leader Dino Maroudias on 07708 808808 or at teamhammersmith@gmail.com.

Nathan's Three Peaks Challenge

If you need a bit of incentivisation to take part in the Transplant Games you need look no further than our own Chair's son Nathan who is embarking on an even bigger personal mission to raise funds and awareness for our WLKPA. Have a quick read of the below which will hopefully inspire you to help or maybe even embark on your own event or fundraiser.



What better way to mark the beginning of my third decade of life, than to push my own personal boundaries and confront my fear of heights (and exercise!). The National Three Peaks Challenge is a strenuous trek, requiring a good level of fitness and stamina (being comfortable with heights also helps!).

The challenge consists of climbing the three highest peaks of Scotland, England and Wales - all within 24 hours! 1st & 2nd September 2018

The total trekking distance is 23 miles (37km), the total ascent is 3064 metres (10,052ft) and if that wasn't testing enough, I plan on doing all of this with a 20kg back pack!

The three mountains are:

- * Ben Nevis, in Scotland (1345m)*
- * Snowdon, in Wales (1085m)*
- * Scafell Pike, in England (978m)*

The 24-hour window includes both trekking time and travel between the mountains—approximately 13 hours trekking and 11 hours driving.

Why West London Kidney Patients Association? - West London Kidney Patients Association played an absolutely pivotal role in supporting my mother and us, her family, throughout her renal journey. Providing emotional, psychological and financial support, West London Kidney Patients' Association ensured that we never lost hope and more importantly never had to compromise on my mother's quality of life.

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Secretary@westlondonkpa.org	Address admin queries or requests for funding/support to this email

Visit:- www.westlondonkpa.org



WLKPA