



West London
Kidney Patients'
Association

Actively involving West London
in renal health issues and care

Registered Charity 275771
June 2016

The West London Kidney Patients' Association June 2016 Newsletter

It's here! Summer has come at last. Well it is supposed to have. As I write this the rain drops are splashing heavily against my window. At least hopefully soon we will be able to have some sunnier weather either here or on another far flung shore. Do remember if you are heading out into the sun to make sure you take all the necessary precautions. For the unaware, patients that have had a transplant – and even those who are waiting for one - need to be careful on hotter days. So follow the Aussie rule of slip, slop, slap. Slip on a shirt, slop on the suncream and slap on a hat! The cute fellow on the left is the chap who used to deliver this message.



As always we hope you enjoy this newsletter. We of course always try to include items of use as well as of interest. I am sure you will find the articles in this edition especially informative – from the Save your Vein campaign through to the new PKD telephone service. Of course there is the usual dietary information and tasty recipe – and some exciting news about the changing face of your KPA.

As always if you would like to know more about what we are up to, offer your support as a volunteer or even get involved with the committee we would love to hear from you. You can reach John Hiney at jhiney2076@aol.com or Sarah Ilic on mum.ilic@gmail.com.

I would like to highlight a couple of key dates for your diary. The first is an Expo that is due to take place at Hammersmith Hospital on 28th September. There is more detail on that event in the article inside. Another important date is that of our AGM which this year is due to happen on the 19th October. We really would like to see more of you there this year.

We're changing.....

A new KPA logo is being introduced over the coming months.



We are proud to announce the arrival of a new look for your KPA. We have decided to update our look with a new logo and design style for our communications. The clean, new look will freshen up our image and also help us to communicate more professionally with everyone that we interact with. The new logo was designed "in-house" by Chetan Joshi and is based on the previous logo rather than

a radical overhaul. Undertaking this sort of task is never easy – so it is a HUGE thanks to Chetan for all his hard work.



The old logo depicted a happy kidney holding hands with a tearful/ sad kidney - this is reflected in the new logo which shows a happy (well perfused) kidney alongside a sad (poorly perfused) kidney. Both are within a circle showing togetherness. We hope you like the new logo which will begin to be featured on leaflets, posters and merchandise as well as on our digital signage screens and website (which is also being refreshed). We'd be delighted to hear from you with your ideas for the website. Look out for the new logo on display around your hospital.

We know a lot of our readers are already on Dialysis. Even those fortunate enough not to be know that maybe one day they will have to face the prospect of it. Should that day come one of the key things we will need are healthy veins to ensure the process is as easy as possible. The article below shows that we can all do something to help ensure that is the case.

Save Your Vein - A Health awareness campaign for renal patients and healthcare staff

As renal disease progresses, patients and their doctors need to start to talk about Renal Replacement Therapy; Treatments which replace the normal blood-filtering function of their failing kidneys.

One of the commonest methods of RRT is haemodialysis; where blood is cycled through an artificial kidney machine before being returned to the body. This requires a form of 'vascular access' which enables blood to be taken from the body and cycled through the dialysis machine. Many forms of vascular access exist, but the 'gold standard' method is the Arterio-Venous Fistula (AVF); a surgically created connection between an artery and a vein. The AVF is superior as it provides the patient with a more efficient dialysis, lower infection rates and an improved quality of life. It is also the only form of vascular access that is completely natural and does not rely on lines or other foreign material to be placed inside the body.



Vein preservation - In order to create a good quality AVF, patients need to protect key veins that are intended for future AVF formation. Every time a needle is placed into a vein (venepuncture) for a blood test or for an intravenous infusion, a small amount of scar tissue is created. With repeated damage, this scar tissue builds up making the creation of an AVF difficult and more likely to fail.

The veins that must be protected are in the elbow crease and at the wrist. Our key message is that wherever possible, venepuncture should be performed in the back of the hand.

The 'Save Your Vein' campaign

Studies performed in a North West London Renal Unit in 2014 showed that the vast majority of both patients and staff were unaware of the need for vein preservation. In response, Mr Jeremy Crane (Consultant Transplant and Vascular Surgeon) and Dr Christine Hall (GP Registrar), Imperial College Healthcare NHS Trust, developed and implemented the 'Save Your Vein' campaign.



'Wherever possible, blood tests should be taken from the back of the hand'

The campaign consists of posters, leaflets, wristbands and alert cards for patients. For staff, the team have provided teaching sessions, written information and lanyards. The alert cards have been a particular success in helping patients to challenge the healthcare professional that is trying to take blood. The campaign has been very successful and is currently in the process of being up scaled for National use thanks to a generous grant from the British Kidney Patient Association (BKPA).

To find out more please follow at:

www.facebook.com/saveyourvein and www.twitter.com/saveyourvein

Dates for your diary

As always we are busy with a whole range of fund and awareness raising activities on your behalf. Below are a few key dates for your diary. It would be great if you are able to join us at one of these events/activities.

Hayes Tombola Stall - Sunday 26th June from 12 - 4.00pm. Join us at the Hayes and Harlington Community Centre, Station Road Hayes, (few yards/metres from Hayes railway station, near to Asda). An abundance of stalls for your perusal, refreshments available come and look us up.

Expo for Kidney patients and Families – Wednesday 28th September – an afternoon of all things related to kidney disease and its treatment (see poster within this newsletter for more details)

WLKPA AGM – 19th October 6.30pm – our annual review of our activities and plans for the coming year

..And a big thank you.... To Vindi Dulku who many of you know as the Live Transplant Co-Ordinator at Hammersmith. Vindi recently undertook a series of talks and information sessions at local temples. This has raised £6,000 for the WLKPA so thank you Vindi and also the Bhadrans Bandhu Samaj UK Charitable Trust and the Karma Yoga Foundation.

As always this year's World Kidney Day activity was a success. We managed to raise over £1,700 with the raffle. Rather than just give a list of names of the winners we thought it would be great to show you one of their stories. Jennie's husband Steve works at Charing Cross where we had one of our fund raising stands.

Jennie's Story

Jennie was diagnosed with Type 1 diabetes at age 19. Nine years ago, aged 43, she went into kidney failure following a severe bout of pneumonia. She spent 3 years on dialysis, first haemodialysis and then peritoneal dialysis supported by Sheffield Kidney Institute. She was then able to receive a kidney from Sandra, her only sister, thanks to the pioneering work on antibody mismatched transplants at Coventry Walsgrave University Hospital.



*Holidays together,
Isle of Wight*



*Sandra & Jennie just
before transplant in 2010*

She is now 6 years post-transplant and still doing really well. She is still diabetic of course, but following the transplant she has been well enough to raise funds for her local charities, Doncaster & Bassetlaw Kidney Association (DaBKA), Sheffield Kidney Institute and Diabetes UK by completing cycle rides, fun runs and even a sky dive!

Sandra's husband Steve, who works in the West London Cancer Clinical Trials unit at Charing Cross Hospital, bought some raffle tickets on Jennie's behalf as all their family know and appreciate the support of Kidney Patient Associations like West London.

She was delighted to win first prize and has decided to share the money between supporting her next her fundraising venture -- a second sky dive --and funding a trip to fulfil a lifelong ambition to see the Northern Lights in Iceland.



*Jennie & Sandra Kidney
Raffle Prize Winner*

As well as the BKPA Survey below, Vassilios Papalois – Consultant Transplant Surgeon at Hammersmith and our Patron - is involved in a collaborative study between three Universities: Imperial College-UK, Erasmus University -Holland, University of Cantabria-Spain.

The aim of the study is to survey the views and attitudes of patients, medical students and administrative healthcare staff regarding deceased organ donation so that they can design effective campaigns that will help to increase the rate of organ donation. The survey is in two parts – a 20 min online questionnaire and then additional focus groups.

By participating in the survey, you will be entered into a prize draw to win one of three £25 Amazon gift cards, and by participating in the focus groups, you will be entered into a prize draw to win one of two £25 Amazon gift cards.

*To take part in this study please contact Maria Theodosopoulou @
m.theodosopoulou12@imperial.ac.uk*

Important opportunities to air your views

The British Kidney Patient Association has teamed up with the UK Renal Registry and NHS England to launch the first ever national survey of patient experience, the PREMs Survey.



*This survey should arrive in units on **6th June** and will allow patients to report on their experience across areas such as communication and support from the renal team, decisions, privacy and dignity, and the environment. The survey has been developed in partnership between patients, carers and health professionals, with the ambition for it to be an annual survey of patients' views. Please do look out for it in your unit and take part.*

THINK KIDNEYS

The National Patient Reported Experience Survey

Your Voice Matters!

- This unit is taking part in an important survey about your care
- Our aim is to improve services for people with kidney disease
- We'd like you to complete the survey to help us
- The survey is completely anonymous
- We'll give you feedback on the results and let you know what actions we're going to take as a result
- What you think really does count. Be honest and help us to help you. Thanks.

One of the things we would really like to offer as a KPA is a members' support system –a simple way for our members to get help, support and input from others who have faced the same problems and challenges as themselves because of Kidney disease. We have been working on this for a while – so hopefully we will be able to update you on our plans soon. In the meantime please have a look at the initiative below from the PKD Charity. Hopefully it will be of benefit for a few people



The PKD Charity Telephone Befriending & Peer Support Project - supporting people affected by ADPKD in London

About PKD Charity Telephone Befriending & Peer Support

The service is funded by a grant from the Big Lottery Awards for All programme in England. The grant is to further support patients, family members and carers affected by polycystic kidney disease. It will be used to deliver a one-year pilot programme in London (and the North West of England). This pilot will enable PKD Charity to determine the effectiveness of such a service before committing to a national programme. The project came about after feedback received at our Patient Information Days across the UK and from calls received to our helpline. It became clear that there was a need for some more tailored and regular support by telephone. The pilot was officially launched on World Kidney Day at King's College Hospital.



Eleri Wood of Kings College launching the service on WKD

What is telephone befriending and peer support?

When going through a difficult time living with Polycystic Kidney Disease (PKD), or experiencing a period of change, sometimes it can be helpful to talk to someone who understands how we feel. A supportive, listening ear and reassurance can help us to feel more confident. Telephone befriending support is now available by trained volunteers to adults affected by Autosomal Dominant Polycystic Kidney Disease (ADPKD) or Autosomal Recessive Polycystic Kidney Disease (ARPKD).



How does it work?

We will phone you to find out about your situation and whether a regular weekly phone call from one of our volunteers would be useful. If possible and appropriate, we'll put you in touch with a volunteer who will phone you for a 20-30 minute chat at the same time every week. You will decide what you want to talk about each week but the volunteer will provide companionship and be able to tell you about services and activities that could benefit you.

Who can apply?	Referrals
Anyone who: f. is over 18 f. lives in the London area f. has ADPKD or ARPKD f. is a family member or carer for someone with ADPKD or ARPKD	You can refer yourself to the service or you can be referred to us by a friend, relative or carer, a health or social care professional, or from another voluntary organisation who knows you. When you are referred to us by someone else, we will contact you directly to have a chat about how the service could help you.

Who to contact?

To find out more, or to apply, please contact Julie Adams on 0300 111 1234 (Mon-Fri 10 am to 4.30pm) or 07739 632836 or email: julie.adams@pkdcharity.org.uk

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