



Actively involving West London in
renal health issues and care

Registered Charity 275771

The West London Kidney Patients' Association Newsletter

February 2017

HAPPY NEW YEAR!!

Seems like only 365 days ago since we last said that!

Well last year was quite a rollercoaster for just about all of us. Whatever your political affinity or leaning you can't say it wasn't a year of surprises. We were given a new PM, we now have a new POTUS (President of the United States – for the uninitiated) and we are busy working on the exit strategy for Europe - whatever that may be. We also lost a whole host of music and acting legends – that coupled with the Olympics, the Paralympics and the European cup it seems we could all do with a less hectic 2017. Mind you having said that you will already see that things with your Kidney Patient Association are set up to be busy throughout the forthcoming year. We have World Kidney Day coming up again in March, we are already talking about the days out for our dialysis patients and before you know it we will be arranging the team for our Transplant Sport participation again.

We look forward to keeping you up to speed with what we are up to throughout the year – we also hope that maybe you will get engaged with some of our activities. Whether it is coming along to one of our meetings or seminars, taking part in one of our raffles or prize draws or just simply trying one of the recipes that we publish in these newsletters. Whichever way you decide to get involved we hope you do just that – get involved.

In the meantime, whatever the year has planned for you this year we hope you all have a healthy and prosperous one with every goal and ambition you want fulfilled.

A proper introduction to Penne

As mentioned in our last update our committee has a new Chair. Many of you will know Penne from her involvement with the WLKPA over the last few years.

Penne has been a huge asset to us since she first became involved with the Charity a few years ago. In stepping into the Chair role Penne has taken on the challenge of helping support and assist you, the patient, your families and carers. No small task!

Penne will obviously need help – if you feel you want to get involved in any way whatsoever, please do feel free to get in touch. Your support and assistance will be very much appreciated no matter what you are able to do.

We look forward to hearing from you: chair@westlondonkpa.org



If music can soothe the soul...



... what impact can it have on the Kidneys?

No, it's not the latest research programme for ultrasound waves or other scientific breakthrough from Imperial's research team.

This the latest funding request that your West London Kidney Patients' Association has supported. We were approached recently by the team at One South, Charing Cross. Following the successful trial at Northwick Park the Charing Cross team wanted to also experiment with the Nordoff-Robbins charity's provision of music therapy on the Dialysis wards. The aim of the therapy is to use music to reduce stress, improve emotional wellbeing, decrease boredom during treatment and increase interaction with others. Given the rigidity and restriction of the Dialysis treatment process we were happy to support this in a bid to improve the situation for the dialysis patents on some of the sessions.

By all accounts the experiment has been a huge success with both patients and staff at the unit. The "roving minstrel" that has engaged and entertained on a few of the sessions has been greatly welcomed and appreciated. Jose Alor is a Nordoff-Robbins music therapist. He has a Master's Degree in music therapy and explained "Music focuses on the healthy part of a person. Patients all enjoy the atmosphere when hearing the music. They make requests and tap and clap along to the tunes. If they know the song some of them sign along. The music brings them happiness".



The patients chat to Jose and recall happy times. The music helps them pass the time and puts them in a good frame of mind. The patients are really enjoying the music, one man said "it doesn't cure me, I still have to dialysis as my transplant failed after one year but Jose take requests and play songs I remember from the past cheers me up and I don't feel so fed up"

One lady who sings at church requested some Blues and Jose played "Oh What a Beautiful Morning" from Oklahoma which she sang along to. Other songs include "Let it Be" and "Swing low sweet chariot" which one lady danced to after she came off her machine!



Sister Linda Ricci and staff nurse Carol Torres, seen singing and dancing with Jose, both said it is really lovely for the patients who cheer up and relax.

Jose started playing relaxing music on his piano/keyboard as most patients were sleeping or resting with their eyes closed. Patients started to stir and I saw they were smiling and one lady, Brenda, who obviously liked the music took her headphones off. Another lady, Lily sang to a well-known tune, "Edelweiss". Patients around her opened their eyes and smiled. She had a beautiful voice and the staff and patients thoroughly enjoyed it. The staff joined it later to "She'll be coming around the mountain"

They all look forward to Tuesdays now. All in all, the therapy is just that - therapeutic. Hopefully there will be additional funds available in the future so that the Mon/Wed/Fri dialysis patients get to benefit from it to.

An invite to St Mary's

How are your visits to your clinic? Do you have to get the bus, the train – both? Is it busy when you arrive – do you find yourself wishing for something a little quieter - a little more peaceful?

Now I may kick myself for suggesting this – but there is such a place. The renal clinics at St Mary's hospital are not as big as those at Hammersmith, they are right next door to Paddington Station – so easy to get to with regular rail services serving most stations in West London. Run efficiently by Sister Jane and her team, this quiet gem is a real find. Given all of this why, you may ask, should I kick myself? Well if you all decide to come along it may ruin the nice peace and quiet for me!

If you feel that you would like to try a different venue for your clinic checkups speak to your consultant to see if appointments at St Mary's would be suitable for you.

Some Fond memories from our former President

After years of sterling service as both a Consultant on the Team at Imperial and also unstinting support year in year out as President of the West London Kidney Patients' Association, Elaine Clutterbuck retired from both positions last year. We asked Elaine to provide us with a few thoughts and recollections on her time in both roles:

"I became a consultant nephrologist at Hammersmith in 1991, and as it is now 6 months since I retired I was asked to write a few reflections!

For many patients kidney disease is sadly a chronic illness that remains with them lifelong. Therefore, as health care workers for renal patients, we have a unique opportunity to develop a relationship with the patients that ideally grows to be one of trust as well as confidence in our medical expertise. It is a privilege as a doctor to not only share in a patient's joy when things go well, but also to stand alongside them supporting them as best we can in the times of adversity.

So as a brand-new consultant in 1991 I went along to the meetings of the then Hammersmith Kidney Patients Association to help me to work in partnership with the patients - and I have attended them ever since! We have worked together seeing the growth in the size of the renal unit, and since 2005 when Charing cross, St Marys and Hammersmith Hospitals merged into the current Imperial Healthcare Trust, so too did the different KPAs join together to form the West London KPA. It was a great honour to be asked to be the President of the KPA following the retirement of the eminent transplant surgeon Prof Gordon Williams. It has been a great inspiration to witness the courage and fortitude with which patients face their illness.

It is amazing to reflect on how much has changed in renal medicine over the years – for the good! Back when I was a medical student in the late 1970s I witnessed nurses making the haemodialysers by hand prior to each session, now they come pre-packed and sterilised! As a junior doctor in Leeds in 1975 we were only allowed to peek through the patients sideroom window as only the Professor was allowed in to see the patient who had just had the first peritoneal dialysis catheter inserted at Leeds! Now peritoneal dialysis is a very well established modality of dialysis offering suitable patients more flexibility than haemodialysis with similarly good outcomes. In the 1980's no one over the age of 50 years was offered dialysis as it wasn't very easy to tolerate and there weren't many facilities. Now it is much better tolerated, and we have struggled over the years to increase resources so that now the *average* age of patients on dialysis is 66 years of age! As a consequence, the unit has grown amazingly - Just looking at those on dialysis: In 1991 Hammersmith only had ~25 haemodialysis patients and ~75 on peritoneal dialysis, looked after by 3 consultants. Now Imperial Trust cares for ~1350 haemo-and peritoneal dialysis patients with nearly 20 consultants. There have been so many improvements in transplantation, especially with the variety of immune suppressing drugs now available which enables us to tailor those used to fit an individual patient's needs to limit rejection, improve transplant longevity and aim to reduce their side effects. We are also better at treating glomerulonephritides and other systemic illnesses that take their toll on the kidneys and limit the progression of renal disease by optimising blood pressure and diabetes treatment and tackling obesity.



Some changes I wasn't so keen on – in particular the computerisation in outpatients! I never learnt to type properly so after years of being able to maintain eye contact with patients and still write my notes, I hated the intrusion of the computer due to my struggle to type with four fingers!



***Water was abundant in 2012
when our captain fought
through icebergs to get us south
of the Antarctic circle***

Some things haven't changed – the desire to work in partnership with patients, trying to be supportive and friendly as possible, and to continue to strive to provide the highest standards of patient care despite the increasing strains imposed by the scarcity of NHS resources.

My patients have always known I love to travel, and I have been so lucky to see so many exciting parts of the world. Travelling while needing dialysis may not always be wise or possible but I would encourage you to discuss it with your nurses and doctors if you are keen to try. With time, careful assessment and planning travel could be possible! It is very rewarding to help patients and their families have a much-needed break too.

Perhaps consider asking to see if arrangements can be made to dialyse at another unit in the UK to gain initial confidence in dialysing away from your usual base. Or why not consider St Anne's holiday dialysis unit at Emsworth which has a dialysis unit in the garden, self-catering flatlets and is free for Imperial patients. (tel: 01243 376514 . website: <http://www.stannesdialysis.co.uk>)



It was also easy to encourage drinking enough water in the sweltering heat of Surname!

I love photography to share the world I have seen with folk back home. I hope many enjoyed the photos of penguins that I saw in South Georgia and the Falklands which were displayed in the Hammersmith outpatients. It was always fun to wear the WLKPA T-shirt and raise awareness of kidney disease if I was away on World Kidney Day. So as WKD 2017 approaches I thought I would share some of those occasions with you:

If on March 9th we could each speak to just one other person to raise awareness of how crucial kidneys are to our health – of the importance of maintaining an adequate fluid intake, controlling blood pressure, diabetes and obesity and encouraging renal

transplantation - between us wouldn't that be an amazing achievement!

Best wishes to you all, and although I have stepped down as their President you will still see me around supporting the WLKPA in their activities! "

Elaine Clutterbuck

World Kidney Day – Thursday 9th MARCH 2017



It's that time of year again, when we set a day aside to acknowledge all the varied issues that we have to cope with as a result of living with kidney disease.

It is an important day in our calendar. The WLKPA uses this day to raise both awareness and funds. When we have enough help and assistance we undertake activities in local shopping centres or supermarkets. Our primary tasks tend to remain within the realms of the units and hospitals. This year we will have stands at both The Renal & Transplant Centre at Hammersmith hospital and on the first floor of Charing Cross hospital. Please do come along and say hello. We will have some new merchandise, raffle tickets and WKD flyers and information leaflets.

If you are unable to get to one of the stands you can still get involved by joining in our WKD Draw. Included with this delivery of the newsletter you will find some raffle tickets – if you would like to enter the draw please follow the instructions on these tickets. We have received donations of some great prizes - please see below for details of some of the goodies that can be won:

£250 Cash Prize

£100 voucher for the Jamie Oliver Cookery school.

One pair of tickets to Newbury Race Course

Three pairs of "Super Dry sunglasses" donated by Feltham Eye Care.

One day complimentary tickets for 5 family members to the Chessington World of Adventure



Chair@westlondonkpa.org	To get involved, join the committee or for general contact please email the Chair
Editor@westlondonkpa.org	For input or commentary on newsletter articles
Info@westlondonkpa.org	General information or requests
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