



Actively involving West London in
renal health issues and care

Registered Charity 275771

The West London Kidney Patients' Association Newsletter

November 2016

Well, Halloween is out of the way, so that must mean it is time to start the usual festive fun and frolics. Hopefully despite all the commercial razzmatazz you will all be able to enjoy a restful and relaxing run up to the holiday season.

2016 will, for a lot of people, be a year of the momentous changes we have seen in a long time. A vote to leave Europe, and as a direct result new Prime Minister; a new, some would say, somewhat surprising choice for US President – and even a new home for the Great British Bake Off!

Well we at the WLKPA don't like to be left out. There has been quite a bit of change for us as well. We have had new members come on board, lots of change at the Trust and also the various Hospitals and units to which you all belong and also change in our leadership and committee. To hear more about that have a look at the article later in these pages.

Whatever changes you have undergone in the last 12 months we hope that they have been positive ones. Of course, for all of us suffering from the challenges of Kidney Disease that is not always the case. So, if 2016 was not so positive for you we hope that 2017 will bring you a better outlook and that you and your family all have a happy and healthy 2017.

IMPORTANT UPDATE

By the time you read this most of you will already be aware of the change detailed below – but if not, and you are due to be visiting clinic at Hammersmith Hospital soon - please see the below update.

Imperial College
Renal & Transplant Outpatients

Imperial College Healthcare NHS Trust

Temporary Clinic re-location

From Monday 28th November 2016 until late summer 2017, this clinic will be moving to a new location on the South Corridor of Hammersmith Hospital.

The South Corridor is the long corridor you enter when coming into the hospital main entrance on Du Cane Road. If you come through that entrance, the new clinic can be reached by turning right down South Corridor. It is directly opposite the main sign for Area 'B' and will be clearly labelled.

This move is part of the hospital's refurbishment of all outpatient areas and will allow extensive work in main outpatients as well as our own clinic area. When we return in 2017, our current clinic will have been completely refurbished and expanded.

We hope you find the temporary arrangements satisfactory and do not experience any inconvenience. We have worked hard to ensure that the area is to a standard that both you and we would expect but will welcome any comments you have to make about it.

This relocation is, as stated, temporary and will result in a much-improved clinic environment for us all to use in the future. As with any change there will also no doubt be some level of disruption so whilst the work is being undertaken please do support the staff and team in their new temporary environment.

Hospital News

In addition to the very sad news that Elaine will no longer be gracing the consulting rooms at Hammersmith and St Charles there has also been an additional couple of changes in the management of the renal team.

We are pleased to announce that there is a new Clinical Director. Dr Darren Parsons has been appointed into this position and now will assume responsibility for medical facilities and direction. In addition to Darren taking on the role of Clinical Director Paula Aubrey is the accountable officer in her role as General Manager. We wish both every success in their respective roles.



Now hopefully the majority of us are all happy with the quality of care and support we receive – I know from all of my conversations with patients that is almost always the case. However, there is always an opportunity to improve and make things better. Quite often the best way of doing that is to look at how other people undertake the same tasks. It is this thinking that was behind the process of the “Peer Review” which we were involved in earlier in the summer.

The basis of the peer review was for each of the main London hospital trusts to review each other and the full range of renal services provided and evaluate the performance of the unit against each of the National standards set. The intention is not to judge or compare in a competitive nature – or deliver school reports on each unit. Instead it is to identify where there are good working practices or methodologies that everyone can adopt – or where there are places that need to improve.

This was no small task – there was a huge amount of work that had to be undertaken by all staff in both the preparation and undertaking of this mammoth challenge. The results were shared at a meeting held in the Great Hall at St Barts with a unique format for the very unique setting. Each trust was invited to host a ‘speed dating’ session where they were able to provide reviews of particular strengths in their service. The KPA and other patients were also involved to give a patient views and experience – if you took part thank you very much for your support.

As a result of the process there is also a report on the findings. We expect to hear more about that shortly and will be able to report on it in a forthcoming issue.

AGM update

As our constitution dictates we hold our Annual General Meeting in October every year. We had another great meeting this year. We gathered in the Conference Centre at Hammersmith Hospital on the 19th for the review of our activity over the last year, the presentation of our accounts to the membership for approval and also talks on areas of interest for the members that are able to attend.

We were very fortunate this year to have two great speakers. Frank Dor – Consultant Transplant Surgeon at West London Renal and Transplant Centre gave us a really “unique” and at times particularly first hand insight into how live kidney transplants are undertaken. This included a brief history of the procedure and also some lovely film footage!!

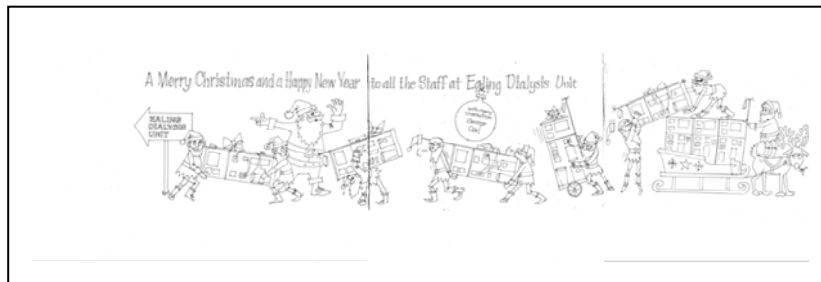
We believe in trying to provide something for everyone and we also had an excellent talk for our dialysis patients. Jeremy Levy – who I am sure a lot of you will know as one of our Nephrology Consultants - gave a great presentation on the past and future of Haemodialysis.

In addition to the presentations we also gave an overview of our activity and shared our accounts for the previous financial year. If you would like to see any of these please do visit our website @ <http://www.westlondonkpa.org/>

Bequest

One very important update at the AGM was the detail on a recent bequest to the WLKPA. We have often discussed within these Newsletters the challenges facing us regarding raising funds to meet our goals to support as many patients as possible. In order to make our funds go further we are constantly undertaking fund raising activities to top up the bank account. Of course, in these financially challenging times money is difficult to come by for everyone. That combined with the well-publicised challenges within the NHS means that as a charity we are in the position of having more calls on us for our support at a time when our ability to raise funds is becoming ever more difficult.

One of the key ways in which we have been helped with funds in recent years is through bequests made by patients in the very unfortunate circumstance of their passing away. It is obviously very sad when we lose any patients - but we are obviously incredibly grateful to them for thinking of us – and so many others - in their kind gesture.



One such patient, who very sadly died in October of last year, was George Cox. George had been dialysing at Ealing Hospital for several years. In 1998, shortly into his retirement, George collapsed and was diagnosed with Kidney Failure. He started dialysis at the unit shortly after. Whilst at the Hospital George was always grateful for the care and consideration he received. One way in which he acknowledged this was through his artistic skills. Each Christmas George created a Christmas card for the staff and others at the unit. The card was hand drawn and then coloured. As it is Christmas we thought it would be great to share one of Georges' designs. We have also thought about using this for one of our Christmas card designs in forthcoming years – if you agree and think this is a good idea please let us know.

Christmas card sales

As it is the end of the year we will all be busy as usual out and about raising funds and awareness at our Christmas card sale events at the various units on our “patch”. These days are important for us as they do provide a really good chance for us to be out and about speaking to people.

As always, we have a good selection of cards so hopefully can cover everyone's preferences. As always all profits from the sales of the cards, and our other merchandise, goes to helping our patient members. Each pack of cards or water bottle sold helps buy crumb cushions for the dialysis patients or help fund the summer days out featured in our previous edition.



If you are able to, please come along and support us – either by volunteering or just popping by to say hello. Of course, if you happen to be needing some Christmas cards as well..... You can see some of the key dates and locations in the poster. By the time you receive this newsletter we would have already undertaken a few of the days – but please do come along – it is always nice to see you.

In addition to cards we will also have a great range of our new promotional materials. In line with the redesign of our logo and communication materials we have badges, pens and all sorts of merchandise that help us get our message about the challenges of Kidney disease out. Perhaps the most charming of this is our new furry helper. We are pleased to introduce one of our new mascots. If you are able to make it along to one of the card sales, we are also selling these – so if you want a gift for that someone special this festive season please do make sure you get along to see us – or email us at info@westlondonkpa.org

Say hello – wave goodbye (well sort of...)

In addition to all the usual updates and information at the AGM it was also time for change in a couple of the existing roles in the committee.

Elaine Clutterbuck has served faithfully as our President for many years. We won't say exactly how many as that would be impolite – but let's just say she has supported 5 different Chairs over the last 20 odd years!



The reason for Elaine's standing down is that she has now retired from her consultant Nephrologist role at Imperial. As a result, she is unable to continue to serve as president due to our rules within the constitution. The good news however is that we will continue to benefit from Elaine's huge experience and insight as an associate committee member. We would like to thank Elaine for all of her hard work and support over the years and also advance thanks for her ongoing dedication to our cause!

In addition to change in the role at president it was also time for a change in the role of Chair. John Hiney has been in the role of Chair for the last 3 years. Whilst stepping down from the role John will continue to serve as a trustee and work with the committee on the various tasks required. John has now handed over the reins of the committee to Penne Sawford who takes over as Chair moving forward. Penne has been a member of the committee for the last 3 years – many will know her through her fantastic work in both helping with the Transplant Sport team and also in organising the summer Day Trips. Penne will give a bit of an update on her thoughts, views and ambitions for the role in the next issue



Penne has been a member of the committee for the last 3 years – many will know her through her fantastic work in both helping with the Transplant Sport team and also in organising the summer Day Trips. Penne will give a bit of an update on her thoughts, views and ambitions for the role in the next issue.

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