



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. October 2014
Visit www.kidneymatters.co.uk

Registered Charity No.513446

Queen Elizabeth Hospital Kidney Patients' Association

The Patients' Association for all Renal Patients treated by the Q.E. Hospital

Patients on HHD, Transplant, and PD

Dialysis Units at Aston, Tipton, Woodgate, Kings Norton, City, Sparkhill, Lichfield,
Worcester, Kidderminster, Hereford, Llandrindod Wells, and U.H.B.

The K.P.A. supports Renal Research at the Q.E. with £23000.



Jane and Nick Flint (KPA), Mr Nick Inston, Len and Joan Ingram (KPA)

Because of the very generous and continuing support that the Q.E.H.K.P.A. receives from kidney patients, friends, relatives and carers of patients and the public in fundraising we are very pleased to be able to support a renal research project being undertaken at the Q.E.

This project will have a direct benefit to the renal patients treated by the Queen Elizabeth Hospital and also involve the patients here.

The Research Project is led by Mr Nick Inston Consultant Renal Surgeon, who is looking at new ways to access patients' blood vessels for dialysis treatment. Mr Inston said: "Kidney disease patients who are on dialysis require access to the blood vessels multiple times a week and this causes the vessels to scar and narrow. This research is looking at ways to improve the success and longevity of vascular access for patients."

"With the generous support of the K.P.A., the Q.E.H.B. Vascular Access Research Group is leading research in this area. This current project is aimed at using a simple drug to open up the veins after surgery and increase the blood flow to enable more successful outcomes and better dialysis."

Mr Inston added: "I'd like to thank the KPA supporters for their generosity. It's a fantastic sum of money which will have a direct positive impact on renal patient care."

Support at our K.P.A. meetings

The K.P.A. meet every month at the Hospital and we welcome new faces. The meetings are very informal and we are all involved with renal conditions. The meetings start at 7.30 and last about 2 hours, It's a good opportunity to talk and meet other patients, to learn about what is going on with renal services in the area and what the K.P.A. is planning.

Attending a meeting does not commit you to active involvement.

Meetings usually take place on the 2nd Wednesday evening each month, but sometimes we do have to change the dates. We put the dates on our website or please phone one of the committee members to check before you come along.

We hope to see you.

Vera holds another Garden Party for the K.P.A

A very loyal supporter of the K.P.A., Vera, whose friend's husband is a renal patient, held another garden party at her house. She has been doing this for a number of years now and it has become an annual event for her. The weather was very good on the day and many people supported her. There were stalls and plant sales and everyone had a great time.

Vera raised £1000 and gave £500 to the Queen Elizabeth Hospital Kidney Patients' Association and £500 to the local Hospice.

Well done and thank you to Vera and all those who helped and supported her.



Naomi raised £1200 having a haircut.



Naomi said: It went really well. My boss offered for us to use the lounge at work (I work in a homeless hostel), so my family came down to Cardiff where I live to do it. (This included my sister, Roxanne Lane, my father, Douglas Lane, and Roxie's three young children). Some of the hostel residents and staff watched and gave us support on the day. It was quite emotional, and a few tears were shed! I have attached some photos for you.

My Fiancé (Stu Vaughan)

was the first to step up for the shave, followed by myself. We were both shaved by my Managers; Chris Bowen and Victoria Lloyd-Jones and we would like to say a big thank you to them for their support.

On the Friday before, my Mum (Candy Lane) announced she would have a Mohican haircut if we could raise another £100 before 12pm on the Saturday. We raised £150, and I had the honour of cutting her hair!!

My sister's three children were there too (Ava, Charlie and Aron), and Charlie had fun playing with my hair after! It is growing back very quickly, but we are getting used to being 'skinheads'!

The K.P.A. thanks Naomi and her family and friends for supporting us and we wish Roxie all the very best with her forthcoming treatment. Naomi asked that the money be split between Research, publishing this magazine and support to patients.



Playstation for the renal ward



Support from Patients

The K.P.A. has received a number of donations recently from around the area. We had a donation from a pupil at Edgbaston school, another from a patient who does after Dinner talks who donated his fee. Next year he is planning a series of after dinner talks at W.I. Meetings. He is donating all the fees from them to us.

We have also had donations from patients who have set up Standing Orders with their Banks to donate monthly. Other donations have come in from collection tins in pubs, Dress Down days and the JustGiving donation via mobile phones.

We are very grateful to all these people who have supported us as it enables us to continue to support the Hospital and Renal Patients.

Thank you to you all from the Queen Elizabeth Hospital Kidney Patients' Association.

Are you unsure if you are active on the kidney transplant list?

The kidney transplant coordinators are happy to answer any queries you have.

Please contact the Hospital.

Phone number 0121 371 4433

Gail Darke, staff member on ward 303, recognised that there was little to do for the younger patients to help pass their time while on ward 303, so she decided to do something about it.

Gail has started to make changes to a waiting room by getting a small dining table and chairs and a couple of settees plus a television. The K.P.A. has provided a Playstation.

One of the young patients received the Playstation from the Chairman of the K.P.A. Nick Flint and said "that he thought the room was great as there was nothing to do all day and to sit and chat to other patients would help."

If anyone has any games for the Playstation PS3 that they have finished with, we would be pleased to have them for the Unit. Please contact the K.P.A. . Details are on the back page.

Transplant Patients please check.

It has been brought to our attention on several occasions recently that when Transplant Patients have visited their G.P. they have found that the G.P. has NOT recorded on their records that they have had a transplant.

On one occasion this has resulted in medication being prescribed that is unsuitable for a transplant patient. So next time you visit your G.P., please ask and check that they have it on your records correctly.

In Memoriam

Our sympathies go to the families and friends of loved ones who have sadly passed away.

We are very grateful for donations sent to help us continue the support for the patients and Hospital. We remember:- Trevor Smith, Gerry Grehan, Michael Gray, Elian Wright and Philip Edwards.

K.P.A. meetings are held at the Queen Elizabeth Hospital on the 2nd Wednesday of each month at 7.30 pm in the New Faith Centre Please check our web site or phone a committee member in case of a change of date.

EVERYONE IS WELCOME. SUPPORT YOUR K.P.A..

Many people have donated to the Queen Elizabeth Hospital Kidney Patients' Association using their mobile phone.

It's a very easy way to help us. If you would like to help

Text **KDNY11 £3 to70070** and this would donate £3 to the K.P.A.

You can choose to donate £1, £2, £3, £5, or £10. by just changing the amount in the message.

Thank you for your support and thanks to those who have already donated.

Please support our Christmas Draw

We have enclosed tickets for our Christmas Draw. This is the only time we ask for support from all Renal Patients. The tickets are 50p each or £5 for the book. Last year we sold over £3250 worth of tickets and we thank everyone who supported us. As you can see from this magazine and earlier ones, all the money raised is for the benefit of Queen Elizabeth Hospital Patients including those who are treated at the 11 dialysis units, those at home on dialysis and also those who have had transplants.

The K.P.A. does not have any paid staff or administration costs as do other renal charities. If we are successful with our fundraising we will be able to continue our support to the Hospital and to you the Patients.

- We have just given £23000 for ongoing research at the Q.E. into improving fistulas. This is already translating into improvements in treatment.
- We have given funding towards the Patient Holiday which

funds an additional member of staff to accompany the group.

- We have been able to fund Patient outings and hope to support Christmas celebrations in the coming months.
- We have been able to provide a Playstation for the younger inpatients to help pass the time while they are in Ward 303.

We are funding the Wifi on ward 301 and we would like to extend this to the other Renal wards in the future.

We can only continue to do this work with the continuing help and support from the Patients, Friends, Carers and Families who have been exceedingly generous over many years supporting our K.P.A. at this Hospital. We would thank everyone who has fundraised for us with haircuts, garden parties, stalls in markets, bring and buy sales, coffee mornings with friends, pub quizzes and the list goes on.

Thank you to everyone who has very generously made donations to the Queen Elizabeth Hospital Kidney Patients' Association.

Patients enjoy sunshine in Crete



This year's renal patient holiday was on the beautiful island of Crete. We stayed in a location called Kata Gouvres in the hotel St Constantin, which was located right near the beachfront. The group ranged from 2 to 72!

Despite being a group of 22 we all did what we wanted to do during the day and then met up during most evenings for a catch up. This included being dragged around the tables doing a Traditional Greek dance!

There was an area near the larger of the two pools which was nicked named 'QE Corner' simply because we would meet to chat or simply sun bathe. Or in Lynda's case watch 'Dexter' (when she could get it downloaded that is!).

The group were fortunate enough to go on a great boat trip which was

organised by the dialysis centre; which incidentally was awarded a five star rating from all that used it. The trip took us out for the day around the Crete coast line and it gave some the opportunity to jump into the warm and very salty sea. More of us floated than swam due to the intense salty sea in this part of the Greek Isles! The beautiful weather allowed others to top up their tan and gave some the opportunity to relax and take in the wonderful scenery. Following a lovely buffet on board, the boat stopped off at a lovely, idyllic island of SISI where light refreshment was taken by all.

On returning to the bus the whole group were relieved to discover that the driver had managed to find the air conditioning button. This was because on the way to the harbour, the driver couldn't turn the heating button off, during the drive

there! I swear the temperature was over a 100 degrees on the bus. This may have help the dialysis patients lose a few litres though!

Another highlight was the BBQ which the hotel management organised weekly. The waiters put together a table plan which allowed the whole group to sit together.

A final big thanks goes to Sharon and Lynda for making the holiday possible. Having them there not only gives that added bit of 'patient security' but they seem to have a knack for remembering to take spare medication and anything else that get generally gets forgotten.

Here's looking forward to next year.....
Lyn Moldrick.

Q.E.H.K.P.A. Tombola at Sainsbury's

Thanks again to Sainsbury's. They allowed us to have a collection and Tombola in their store on Saturday June 28th. This has become a bi-annual fundraising event.

We were there from 9.00 until 4.00, and we were supported by Joanne and Shemimu from Lloyds Bank Birmingham who came along to help the members of the K.P.A. We were very well supported by the public and we raised £610. We thank Sainsbury's and their customers for being so generous with their support.

We will be having another collection on 29th November. If you can spare an hour or so to help us, please contact one of the committee. Contact details are on the back page.



New Units at Aston, Great Bridge, Kings Norton and Hereford: Update by Diaverum

There has been lots of activity over the summer, and we are really pleased with the progress that has been made. Our first building at Great Bridge was handed over in mid September. The builders are busy making those finishing touches. On the 15th of September, we will have receive our first deliveries of the Dialysis machines and all the new furniture.

The handover of the Kings Norton site followed on the 26th of September and Hereford and Aston will be ready in October.

It was a privilege to be able to show staff around the new sites, one member of staff who will be working with us at the Hereford unit described the unit as "it is amazing, really spacious, and nicer than we could have imagined."

We have since had some queries from patients who will be transferring over to the new units asking when they can visit. We have arranged some dates which I hope you will have been able to attend, I hope they all met your expectations.

The dates for the visits for the Aston unit areas follows:-

Aston – 4-6pm on 30th Oct and 10am -12 midday on the 31st Oct.

Please drop in at any time during the hours above where there will be a member of the Diaverum team to show you

around.

We have also had some requests to see the pictures of the Uniforms that our Nurses wear and pictures of the Dialysis machines and chairs. These have all been posted onto our website on the link for you below:

<http://www.diaverum.com/en-GB/Diaverum-UK/Diaverum-in-the-West-Midlands/>

For those of you who are unable to visit the sites before we open on the 3rd of November, University Hospitals Birmingham have kindly agreed to provide a virtual tour of the unit that again we will place on our website. This will enable you to see exactly what the unit will look like from the comfort of your own home!

Whilst the building work has been progressing, our clinical team have also been making plans ready for your first Dialysis Treatment with us. Where possible our clinical policies have been aligned with those at the hospital, and plans for the training and ongoing development of the nurses are being put into place.

Our Practice Development Nurse has been spending some time at the hospital working with the clinical team to ensure a seamless pathway of care for patients.

Our training programme for the new nurses that we are recruiting began on the 6th of October. They will receive 4 weeks of intensive training prior to the units opening. As Great Bridge will be the first site to be ready, this will all be done there.

We will also have some dates for staff to come and be trained on the new machines. We will let you know the dates and times of these sessions as soon as they have been finalised.

Diaverum will also have a support team on each site for the first few weeks of opening. This will enable staff to have hands on training and support as they need it. The support team will be made up of experienced staff from our existing units, as well as nurses from the Hospital and Baxter Gambro who will be giving machine training.

We will also have medical support from the Consultants at the hospital who will all be known to you.

We look forward to seeing you all soon, but in the meantime if you have any queries, please do not hesitate to contact me.

**Kim Beak Project Manager,
Diaverum UK
Kim.beah@diaverum.com
07872150327**

Diaverum and Staff at the Hospital have worked very hard over recent months to ensure that the new units are the very best for patients. Changes can be an anxious time so please feel free to contact Kim Beak, Diaverum UK, or the K.P.A. and we will do our best to make the move as comfortable as possible.

Queen Elizabeth Hospital Kidney Patients' Association

Donations by Cheques

Will you please make all cheques payable to Queen Elizabeth Hospital Kidney Patients' Association or Q.E.H.K.P.A.. Money can be ring fenced for a specific purpose or unit.

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