



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. June 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.,

Young Adult Weekend

Two young renal patients went on an adventure weekend organised by **Transplant Sport**. It was held in Oxford on the 25-27th April.

The aim of the weekend was to bring together young dialysis and transplant patients in a social and engaging environment. Thirty young patients from all-over the country attended. The activities included rock climbing, football, racquets sport, 10 pin bowling and pool. The boys had a great time and were pleased to be able to attend.

The weekend highlighted that transplantation can enable patients to carry on a near normal and active life style. The two young men who went from U.H.B. now hope to enter the British Transplant Games to be held in Bolton on 7-10 August.

Mark Thompson from the Q.E who organised the weekend thanked the K.P.A. for making this weekend possible.



WiFi on 301

In the last issue of Kidney Matters it was reported that WiFi was due to start in February. It did not happen. We are now informed that it will start during May. Testing of the system is currently being conducted, so I hope when you read this, it is up and running. We would be interested in your comments about the service and if you find it beneficial.

Wifi will be free for Renal patients. The costs are being paid for by the K.P.A. and U.H.B. Charities. We hope you enjoy the service.

Nick Flint Email:- flintnf@aol.com

More from the Dietitians

There are some more items about healthy eating and ideas for recipes for people on a renal diet on our web site www.kidneymatters.co.uk . Copies of the leaflets can also be obtained from the dialysis units.

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..

Notice is hereby given that the Annual General Meeting of the Queen Elizabeth Hospital Kidney Patients' Association will be held in the Faith Centre of the Queen Elizabeth on Wednesday 9th July 2014 at 7.30p.m.

AGENDA

1. Apologies for absence
2. Minutes of the last A.G.M. held on Wednesday 12th June 2013
3. Matters arising
4. Chairman's report
5. Treasurer's report
6. Election of Officers and Committee
7. Appointment of Auditors
8. Any other business

For and on behalf of the Association Joan Ingram, Secretary

Nomination forms are available from the Secretary or on our Web site.

Please return to the Secretary, or bring to the A.G.M.

Joan Ingram, Secretary Q.E.H.K.P.A.

6 Cremorne Road Sutton Coldfield West Midlands B75 5AW



Your K.P.A.

How about coming along to our meetings and meet members of the K.P.A. .. We meet on the 2nd Wednesday at 7.30 in The Faith Centre at the Q.E.

You will be made very welcome. We all have experience of renal issues, dialysis, transplantation and being donors, and carers. You might find it helps to just come along and chat with others.

Details of where and times are on the front page. **Hope to see you sometime.**

The New Dialysis Units - Kim Beak, Diaverum

Diaverum are really pleased to be working in partnership with University Hospitals Birmingham. We will be opening Dialysis units on 4 sites across the West Midlands in November 2014.

Diaverum currently have clinics in 12 locations across the UK. In Europe we have 274 clinics in 19 different countries.

The clinics have been designed following feedback given by patients to the hospital Trust. The design of each unit will ensure we provide a warm, spacious and homely environment. Each will be fitted with new state of the art equipment and will have individual televisions for patients,

Wi-Fi access, and dedicated patient and staff parking.

The contact will be for a period of 12 years and we will be transferring staff who are currently looking after patients to ensure there is continuity of patient care. We will also be looking for new staff, Registered Nurses and Health Care Assistants, to come and work with us as well.

For further information please visit our website:

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

or contact Kim Beak – Project Manager

kim.beak@diaverum.com



Computer pictures of the new units

Update from Dr. Clara Day

As I am sure everyone is now aware, four of our dialysis units will be moving to brand new homes in November this year. Tipton, Aston Cross, Kings Norton and Hereford are all moving to new units and will then be run by Diaverum, a different dialysis company. All these new units are close to the current ones; a couple of them can be seen from the units! The Aston and Tipton units will be a little smaller than they are at the moment but we hope that transfer across will not mean any shift changes for current patients. Building work has now started at all these sites and the initial plans look great with more space, good parking and individual TVs.

The QE run unit in Smethwick is due to open in mid 2015 and will be for patients currently in the City unit and

also for patients in Tipton or other units who live closer to Smethwick than their current unit. We will obviously discuss this individually with people nearer the time but if you are interested in moving to this unit do let us know. I cannot as yet divulge the exact location but I hope to be able to do so soon.

We have not forgotten about Redditch and will be sorting plans for a unit within the next few months which we will share with you when we have more information.

Please do be in touch with us via kidneypatient@uhb.nhs.uk. Monthly newsletters will also come out from us to all dialysis patients whilst we undergo these changes. Copies of these will be available on the QE and KPA websites.

Clara Day, Nephrology Consultant U.H.B. Birmingham

Update on a project the K.P.A. funded – Dr N. Instone

An update on the research study that the K.P.A. funded last year. The study has recruited over 100 patients and are due to complete the interim review board very soon.

Researchers anticipate this will suggest that the study is continued to reach 200 patients.

This is great news and will make it the biggest well designed vascular access drug study worldwide.

This puts the Queen Elizabeth Hospital Birmingham in a unique situation and will attract further studies to the benefit of Q.E.H.B.. renal patients.

This study has contributed to bringing the wait time for a working AV fistula right down to 7 weeks from over 3 months and gives outcomes that are some of the best in Europe and the World.

We are proud of this and the help from the Queen Elizabeth Hospital Kidney Patients' Association.

Nicholas Inston, Renal Surgery Consultant U.H.B.

In Memoriam

The K.P.A. would like to thank all friends and families who have made donations to us in memory of loved ones. These include Pamela Hemmingway, Ivor Morris, Anthony Gittins and Mr S. Turner.

Our sympathies from the Q.E.H.K.P. go to their families.

Patient Transport

Patient transport for Renal patients has always been a topic of conversation because those who use it need it and have to depend upon it for treatment 3 times every week. The Hospital currently spends about £5million pounds a year to provide Patient Transport. Over 200,000 journeys are made annually, not only for renal patients but all patients who need transport to and from the Queen Elizabeth Hospital for very many types of treatment.

The difficulties that the W.M.A.S. face are that Renal patients need to be transported at times of the day which are the busiest for traffic conditions.

Patient transport, None Emergency Patient Transport (N.E.P.T.) is provided to patients who due to their medical condition are unable to drive themselves to and from Hospital or are medically unfit to use public transport. Also in special circumstances if the journey is unable to be made by any other means. Transport cannot be provided just because a patient wants it.

Update from Adam Layland, W.M.A.S.

Most patients receiving transportation will be transported by West Midlands Ambulance Service NHS Foundation Trust. The 116 strong team operate predominantly all over the Birmingham area and in December last year, Adam Layland was appointed as the Senior Contract Manager. He said "We recognise that there are some improvements to be made regarding the transportation of patients, especially patients who travel regularly with our service. My team and I are dedicated to ensure that patients receive the best service possible and I'm pleased that we have been able to implement a lot of initiatives to improve the service so far. I'm really keen to hear of anybody's suggestions, comments, criticism or compliments so please do not hesitate to get in touch with me by email adam.layland@wmas.nhs.uk or alternatively I will be arranging to visit all the renal units over the coming months. If there is a specific time or day you think I should attend, please let me know."

Update on Immunosuppressant for transplant patients – Dr S. Ball

The immunosuppression message is that there is no immediate change. We are working with NHS England and with patient representatives such as the Q.E.H.K.P.A. to design a system that offers patients easy access to their immunosuppression medication and without having extra visits to the Hospital or clinic visits.

Any system will however involve immunosuppression being provided through the hospital and all other medications through the GP. Again we are working on how best to ensure that the GP is always aware that this medication being prescribed, not only in the early stages following a transplant but in the years following.

There will be no sudden changes, but a careful period of consultation with all involved, followed by communication of our plans to all the patients.

Dr. Simon Ball, Consultant Nephrologist U.H.B.

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

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

We will be there from 9.30 til 4.00. We would welcome any help on the day, so if you could spare an hour please contact Len Ingram and go on the rota. His contact details are on the back page. We often raise about £500 at this event so it is an important part of our funding. If you can spare the time please help.



World Kidney Day, March 2014



The K.P.A. organised a Renal Awareness Day in the Atrium of the Queen Elizabeth Hospital from 9.30 until 4.00pm. We had information about the K.P.A. and the services of the Renal unit at the Hospital. The event was very well supported by the Renal Departments of the Hospital. The Dietitians had plenty of advice for eating well on a renal diet. The C.A.P.D. staff were on hand demonstrating dialysis treatment. Kidney Research were promoting their current project to increase the number of Asian people on the organ donor register. The Renal Research department showed some of the work they were doing to

improve treatments for renal patients. Haemodialysis staff had on display a Dialysis machine and information for patients.

We had very many patients and carers show an interest on the day and many said that they welcomed the opportunity to talk to staff about the issues of renal failure.

The K.P.A. would like to thank all the members of the Renal department for their help and support in making the day a great success.

British Kidney Patient Association – making the difference

The BKPA is the leading grant-giving charity for kidney patients in the UK. We work to improve the daily quality of life for kidney patients and their families.

We're the largest provider of patient grants to those on low income, helping with welfare and domestic costs

We support numerous projects in renal units to help improve patient care and patient facilities

We support national research projects that will help to improve quality of patient care, working for example with the British Renal Society and other kidney charities

We offer patient information and support

We fund short breaks and holidays for children, adults and their families

We have a Facebook Group and active social media

We have a counselling support line

We stand up for your rights at a national level

Each year, we supply up to £2.5 million in grants. We support local Kidney Patient Association activities and your members.

The BKPA is here to help you. To find out more about the BKPA visit our website. www.britishkidney-pa.co.uk Or call us on Tel 01420 541424 or contact info@britishkidney-pa.co.uk



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.

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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