



# KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. May 2012  
Visit [www.kidneymatters.co.uk](http://www.kidneymatters.co.uk)

## 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, Hereford, Llandrindod Wells, and U.H.B.,

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Kidney Matters is now being mailed to all 2200 Renal Patients treated by the Q.E. The cost of stamps alone is £1100. If you would like to help with this cost you can easily support us by Texting **KDNY11 £3 to 70070** and this would donate £3 to the K.P.A.

You can choose to donate £1, £2, £3, £5, or £10.

Thank you for your support and we hope you enjoy reading the magazine.

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### Fresenius and the Dialysis Units.

Many of you will know about the staff changes at the Dialysis Units. The K.P.A. have been, and are still meeting with the Trust to find a solution to this problem. The Trust is very anxious to see the matter resolved and are working hard to this end. They are having regular meetings with Fresenius and monitoring the situation closely.

It is very regretful that patients have had inconvenience and disruption to their treatment. It is a very worrying time and is causing enormous and unnecessary anxiety to many Patients who should not have these concerns. It is hard enough being on Dialysis without these additional uncertainties. We hope these problems will not continue and a solution will be found quickly.

It is useful for us to have details about any experience you have had that you consider unreasonable. All your information will be treated in confidence, but your comments and reports will help in our efforts to ensure you have the best experience when dialysing

If you have any concerns or would like contact me please do so. My contact details are on the back page, or if you wish, please write to the Hospital. Please address your letter to:-

Dr C.Day, Consultant, Renal Department, Queen Elizabeth Hospital, Edgbaston, Birmingham. B15 2PR

### End of an Era

I was walking up the Hospital drive a week ago and saw the end of the Old RDU at the (old ) Q.E. I don't know how long the 'temporary ' Unit had been there.

I first saw the unit in 1995. Maybe someone will remember it opening?



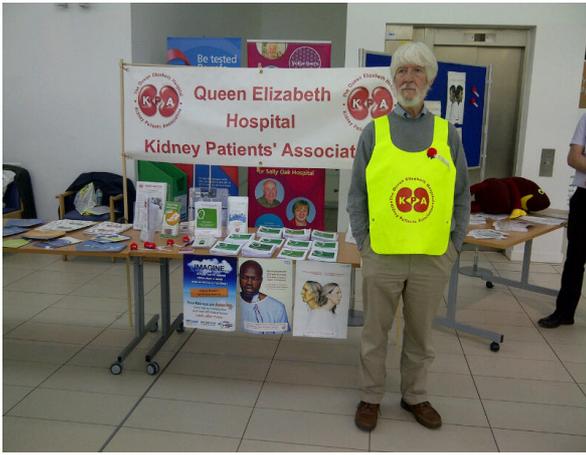
The Queen Elizabeth Hospital Kidney Patients' Association is extremely grateful for all the hard work and generosity of patients and friends who work very hard to raise money for our charity. The money is used to support patients and the Hospital. The Q.E. has a large renal research programme which we also support.

The Q.E. covers a large area and treats 2200 patients who are on dialysis or who have had a transplant  
The K.P.A. is here for you all.

K.P.A. meetings are held at the Queen Elizabeth Hospital  
on the 2<sup>nd</sup> Wednesday of each month at 7.30 pm in  
the New Faith Centre  
**EVERYONE IS WELCOME. SUPPORT YOUR  
K.P.A..**

**Please note.** During the summer months we may have to change the date of our meeting, so if you are not a regular member, please phone one of the committee members to check the dates.

## World Kidney Day March 8th



This year World Kidney Day was on Thursday March 8th. The K.P.A., together with the Renal Department at U.H.B., had a stand in the main Atrium of the Hospital. We distributed Patient Information Leaflets to Patients and promoted the Queen Elizabeth Hospital Kidney Patients' Association. We were very well supported by the Hospital which brought along a Dialysis Machine and other equipment which enabled the public to see what dialysis is all about.

Patients could talk to staff informally about treatment and 3 newly transplanted patients came and shared their delight at such a special time. We also had a machine to test the blood flow of people to check if they were healthy. I am pleased to say no-one was diagnosed with a problem.

We would like to thank the Q.E. for their support and allowing us to use the Atrium. We hope to be back again on World Kidney Day 2013.

**Fundraising** The K.P.A. will be organising a fundraising collection at Sainsburys Walsall on Saturday 23rd June. If anyone would like to support us, please contact a member of the K.P.A. Committee.

## Home Haemodialysis Patient Event

An evening for Home Haemodialysis Patients was organised by the Hospital on 26th April. This gave the patients who dialyse at home the opportunity to meet each other and share ideas and experiences. There were presentations from the K.P.A., the renal dieticians, members of staff from the home dialysis team and Dr Day. An excellent buffet was provided, and a good evening was had by all. There are currently 49 patients doing Home Dialysis and this has increased from 18 in just over 12 months. Home Dialysis gives patients more freedom and choice in dialysing as you can choose the time of day that suits you best, enabling you to fit dialysis around your life and not fitting your life round dialysis. If you are interested in exploring the idea of home dialysis, contact the Renal Unit at the Q.E. for more information.

## Local fundraising

We were very pleased to receive donations from friends of Mrs Goulding who very generously supported the K.P.A. Mrs Masters organised a Christmas stall to sell cards and other homemade decorations and sent us a cheque for £300.

Another of Mrs Goulding's neighbours Mr and Mrs Handy, celebrated their 60th Wedding Anniversary recently and received donations in lieu of gifts and they chose us as one of their beneficiaries. Thank you for your donation of £100.

## Have you registered for Renal Patient View

This is a very useful service. Renal Patients can view and keep track of their Blood Results at home on their computers. Your latest results are posted on-line about 24 hours after clinic. To register, ask for details at your next appointment or phone Renal Outpatients for the forms.

It saves time for you and the Hospital if you check your results on-line.

## Transplant Co-ordinators at the Q.E.

There have been lots of exciting new changes and members within the Renal Transplant Team at the Queen Elizabeth Hospital who overall achieve approx 130 renal transplants a year.

The recipient and living donor team is now led by Sue Moore whose role will be changing. After many years experience in the living donor programme, to oversee all renal transplant co-ordination at QEH. This change means closer working relationships within the team between living and recipient co-ordinators, improving the service they provide and resulting in added benefits for patients.

Each dialysis unit or area now has a named recipient and living donor co-ordinator who will work together reviewing patients in their area. Each patient with a potential living donor will have a named co-ordinator who will guide them through the living donor pathway while the named recipient co-ordinator will ensure the patient has had all investigations and transplant issues addressed.

Another exciting new development to the team has been the addition of Mark Thompson, a youth worker, dedicated to working with our young renal patients aged 16 – 23 years, both transplant and non transplant who

need support in the transition from child services to adult services.

There are many exciting new developments within the service, with Surinder Jandu from the recipient team now working solely with Dr Ball reviewing the blood group incompatible recipients, the paired exchange programme and looking in the future at possible advances in these areas of transplantation.

### Your renal transplant co-ordination team:

Sue Moore – Team Leader and Living Donor Co-ordinator  
Mark Thompson- Youth Worker  
Surinder Jandu – Antibody Incompatible Transplant Coordinator  
Sheryl Parsons- Living Donor Co-ordinator  
Mel Manley- Living Donor Co-ordinator  
Laura Ludman- Living Donor Co-ordinator  
Diane Price – Recipient Co-ordinator  
Katharine Hannon – Recipient Co-ordinator  
Yvonne Myers – Recipient Co-ordinator ( currently on leave)  
Michelle Hurley- Living Donor Team Administrator  
Sybil Pritchard – Recipient Team Administrator  
*Article submitted by the Transplant Co-ordination Team*

# WHAT IT MEANS TO TAKE PART IN A RESEARCH STUDY

In the last article, I outlined why we need to do research and the types of studies that the QEHB get involved in.

This article will discuss the selection of people to take part in studies, why some studies alter your treatment and some don't, what randomisation means and what happens at the end of a study.

All research has to be approved by an ethics committee and it also has to follow guidelines that ensure that the participant's interests and wellbeing are protected throughout a study.

Research studies can take many different formats and I will pick out the main types:

## OBSERVATIONAL STUDIES

These studies do not alter your normal treatment, but aim to collect data about you as your normal care continues. They often carry on for many years.

Some of the data collected is in addition to your normal care and involves extra tests but doesn't alter your treatment.

## INTERVENTIONAL STUDIES

This means that something about your normal care is altered. It could be that you take a new drug, or have a different pattern to your normal care.

The study often involves you being allocated to one of 2 treatment groups. For instance, one group will take a new study drug and the other group will either have a dummy drug (placebo) or perhaps the standard accepted treatment for that condition. These studies are called randomised controlled trials because the group allocation happens outside the research doctors' control. The group is decided by a pre-programmed computer system. This is so that the researcher cannot influence which group you go into and this is one way of helping ensure that he doesn't influence, or bias, the results.

Some of these studies are called "double blinded randomised controlled trials" which means that neither the study team nor the participants know which treatment is allocated. This helps to ensure that the trial results will be entirely without influence by the manufacturers of the new drug.

## SELECTION OF SUBJECTS TO ENTER A STUDY

Each study decides in advance the characteristics of the patients that need to be studied. This means that you will be approached to take part if you have the features that are important to that particular study. For instance, age limits may need to be placed, blood pressure limits, blood results and certain disease characteristics. Generally a list of potential subjects is generated by the research team. Sometimes patients have information sent out in the post about the study and sometimes they are approached in the clinics by the research team.

This information will have been written specifically for the study and will have been reviewed by an ethics committee. It has to cover quite a lot of subject headings and this often makes them a bit long and not that easy to understand. There will always be a phone number on the information sheet to talk to someone about the study, but there is always time to discuss it again face to face with the researchers when a decision is made by the patient about if they want to take part. If they do, a consent form is signed by both the patient and the researcher. Although we obviously want people to take part in research we do recognise that not everyone approached will want to for a variety of reasons. Your care is not affected if you decide

to say no and you also have the right to withdraw at any time in the study.

## WHAT HAPPENS NEXT

Each study will have its own specific pathway for each patient. Sometimes it involves giving extra time at your normal clinics so that extra procedures can be done. For instance, extra blood samples or filling out questionnaires, having extra examinations or tests like an ECG (a painless procedure which looks at heart rhythms. Sometimes it also involves extra visits to clinic especially to see the researcher. If this is the case, the extra transport costs can be claimed.

If the study involves a new drug or a new dose of a drug, the participant is sometimes asked to keep a simple diary and a record of the number of pills taken. Close monitoring can involve telephone calls from the study team to the person taking part.

This often means that the research team and the participant get to know each other quite well throughout the course of a study which is certainly very satisfying for the researcher, but many patients have said they felt they have had "special" care over and above the normal when they are in a study. The research team are very aware of the time and effort that patients give to take part and would wish to make the journey through a study as good as possible.

## THE END OF THE STUDY

If you have taken part in a study which hasn't altered your normal care, you will be told when your part has finished and thanked for taking part. You will also be directed to where the study results are likely to be published. This can often take some time after the end of a patient's participation because all the data has to be analysed and written up before it can be published. Even if you had finished your part in the study, sometimes others will be continued to be followed up for some years so delaying still further you hearing anything about the results. All the renal consultants at the QEHB are very committed to research and it is therefore very likely that at some stage you will be approached to take part in a study. As I mentioned in the first article, research is one of the main ways we can make progress in your treatment and care. Many of the treatments and ways we look after you today have come about because other patients with kidney problems have taken part in research studies in the past.

Increasingly, we are looking to involve patients in the research planning process and we will be asking for volunteers who are interested to make contact.

*Mary Dutton Senior Sister Renal Research U.H.B.*

As before, if you have any questions or would like to be involved in any way, please email Mary Dutton, Senior Sister Renal Research or phone 0121 371 2000 ex 3287

Useful websites:

[http://www.healthtalkonline.org/medical\\_research/](http://www.healthtalkonline.org/medical_research/)

A copy of the first article is available on our web page in the February Newsletter

# NOTICE Queen Elizabeth Hospital Kidney Patients' Association ANNUAL GENERAL MEETING

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 Hospital Birmingham  
on Wednesday 11th JULY 2012 at 7.30 p.m.

## **AGENDA**

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|---|---------------------------------------|
| 1. Apologies for absence  | 5. Treasurer's report                 |
| 2. Minutes of the last A.G.M. held on 8 <sup>th</sup> June 2011 | 6. Election of Officers and Committee |
| 3. Matters arising  | 7. Appointment of Auditors            |
| 4. Chairman's report  | 8. Any other business                 |

*Nominations for Officers or Committee Members should be proposed and seconded and sent to our Secretary before the start of the A.G.M.*

*For and on behalf of the Association **Joan Ingram, Secretary***

### **The Donor Family Network THE PRECIOUS GIFT SERVICE**

A Service of Hope and Thanksgiving  
marking the start of National Transplant Week .  
Donors, recipients, families, professionals and  
anyone interested in organ and tissue donation  
are welcome.

**SUNDAY 1st JULY 2012 2PM  
ST MARGARET'S CHURCH**

**Chapel Lane, Great Barr, Birmingham**

Followed by refreshments at the  
Memorial Hall, Chapel Lane

Directions - Junction 7 M6 – A34 towards Walsall.  
First intersection on right Chapel Lane.  
Church, 400 yards on the right

### **In Memory**

We thank families and friends who send us donations in memory of loved ones.  
Mr Savell recently passed away and we have received a donation of £726.  
In memory of Mrs Coates we received £221 in lieu of flowers.  
Thank you for supporting us at such a difficult time and our thoughts are with you all.

### **E-Petition for patients to register their concerns**

One of our dialysis patients who feels very angry about what is going on at some of the dialysis units has started an E-Petition to highlight the problems and issues that some dialysis patients are having. The contact information is below. To sign up, please go the web site. It is a safe government web site.

To read the petition and to sign up for it please go to the following web address

<http://epetitions.direct.gov.uk/petitions/33063>

## **Patient Information**

**List of Patient Information Titles. All approved by U.H.B.**

Visit our website [www.kidneymatters.co.uk](http://www.kidneymatters.co.uk) to print them out or ask for them at Out Patients at the Q.E.

What is the Q.E. Kidney Patients Association  
Useful Info and Sources of information & Advice  
Healthy Living for people with CKD  
How to Control Phosphate Levels  
What is Polycystic Kidney Disease  
LMBBS Clinic  
Urokinase (Syner-Kinase) treatment  
Cystinuria Patient Information  
Conservative Kidney Management  
What is Vascular Access

Where will I have my Haemodialysis  
Haemodialysis. Line Insertion  
Temporary Haemodialysis Away From Home  
Risks of having Haemodialysis Abroad  
Haemodialysis at Home - Patients Views  
Common Medication - Haemodialysis  
Dietary Advice High Potassium ,  
Haemodialysis  
Haemodialysis. Know your Blood Results  
Keeping Health. Reduce infection.  
Haemodialysis

Haemodialysis. Having Line removed  
Testing for HIV. Patients with CKD  
Going on Holiday. Peritoneal Dialysis  
Pre Transplant Information  
Plasma Exchange  
After Transplant information  
Having a Biopsy  
Peer Support  
Live Donation. Claiming Expenses.  
Young Patients. The move from the Childrens Hospital  
Young Patient at the Q.E. Youth Worker

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