



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. February 2012

Registered Charity No.513446

Visit www.kidneymatters.co.uk

Queen Elizabeth Hospital Kidney Patients' Association

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

Dialysis Centres at

Aston, Tipton, Woodgate, Kings Norton, City, Lichfield, Worcester, Hereford, U.H.B., On Home H.D., Transplants, & PD.

K.P.A. Annual Draw Raised £3800

Congratulations to each and every one of you who bought and sold tickets to help us raise this tremendous sum.

The draw took place on 11th January 2012. Mark Thompson from U.H.B. drew the tickets together with a family member of a patient who visited our meeting. The winning numbers are detailed below and all the winners have been notified.

A patient's husband sold a record number of tickets - over £550, which is an amazing effort. Very well done and thank you.

The grand total from sales of tickets is a record £3849.

Thank you to the large number of patients, carers and friends who supported the Queen Elizabeth Hospital Kidney Patients' Association Christmas Draw again this year. We also thank those who made donations to our fund.



Winning tickets drawn at the Queen Elizabeth Hospital Kidney Patients' Association meeting on Wednesday 11th January 2012 All winners will be notified.

Prize Order	Ticket No.	Winnings	Name	Area
1 st Prize	11694	£300	Mr Thompson	Walsall
2 nd Prize	24101	£150	Ms Maslen	Northfield
3 rd prize	33907	£75	Mr Tamang	Handsworth
4 th Prize	08259	£10	Ms Bulter-Roscilly	Hereford
5 th Prize	39506	£10	Mr Janagal	W. Bromwich
6 th Prize	44826	£10	Mr Allbut	Oldbury
7 th Prize	00830	£10	Mrs Carr	Leominster
8 th Prize	19139	£10	Mrs Patel	Wylde Green
9 th	44200	Recipe Book	Mr Firman	Bourneville
10 th	01164	Recipe Book	Ms Berry	Malvern
11 th	08999	Recipe Book	Mr Chanda	London
12 th	32332	Recipe Book	Mrs Sutor	Redditch
13 th	05033	Recipe Book	Mrs Giles	Oldbury

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 area and the number of patients the K.P.A. covers is very large, with over 2200 patients either on dialysis or with a transplant from all over the Midlands.

New Home for the K.P.A.

The K.P.A. has found a new home after meeting in the Old Hospital for 30 years. We now hold our meetings in the new Faith Centre at the New Queen Elizabeth Hospital.

We are still meeting on the second Wednesday of each month at 7.30pm. The Faith Centre is located in the Atrium above Costa Coffee. Go up the stairs, which are to the left of the main reception desk, to the first floor. The Faith Centre is round to your right. There is also a lift located behind the reception desk.

If you have difficulty in finding us, please ask at the desk.

We welcome any patient or carer who would like to pop in and join our meeting. If you are an inpatient and are able to walk down, please drop in.

We are hoping to have members of the renal team attending the meetings to talk about a range of topics that will be of interest to renal patients and carers.

Hope to see you at our next meeting

Tombola in Sainsburys



This has become a bi-annual event for the K.P.A. and very successful it is proving. We again had the support of Dawn's Mum who works hard gathering prizes and preparing for the big day.

Sainsburys are very generous in allowing us to use the store twice a year for this event. The support from members of the public is tremendous and we raised £506 for the K.P.A. in December

It is very rewarding collecting in this way, as many members of the public talk to us about their excellent experiences at the Queen Elizabeth Hospital.

Our thanks to all those who supported us and to Sainsburys' Customers

LLandrindod Wells Dialysis Unit opens for holiday breaks.

In March, a dialysis unit at LLandrindod Wells will be opening. It will have 4 Stations, 3 of them will be for patients living in the region for regular dialysis. The 4th Station will be available for patients at the Q.E., satellite units or on home dialysis for a holiday, either to take a short break or for a week.

The area has lovely countryside and there are plenty of hotels, B & B's, pubs and caravan sites close by to choose from. It is an ideal place to take a break. As a patient at Q.E., it will be simple to organize. Check that the space is available, and organize your own accommodation. The unit is run by the Q.E so they will have all your medical details on hand. If you have never felt confident about going on holiday, this is a good opportunity to start. If you are interested, contact your Renal Co-ordinator at the Q.E. and book a holiday.

There is no charge for the dialysis treatment but patients must provide their own accommodation and transport to and from the unit.

Please take this opportunity to have a holiday.

For accommodation contact the Tourist Information Office. The Old Town Hall, Memorial Gardens, LLandrindod Wells, Powys. LD1 5DL Phone No:- 01597 822600

Home Haemodialysis

Home Haemodialysis is becoming more popular. More patients of all ages are choosing to have dialysis in the comfort of their own home and at a time that suits them. Patients range in age from 23 to 82. Some work full time, others just appreciate the fact that they don't have to travel to a dialysis unit.

There are many advantages: Choosing the time of day to dialyse; having more free time as there is no travelling to and from the unit; dialysis to suit you; no more patient transport.

These are some comments from patients who have changed to Home Haemodialysis:-

"It took us a long time to agree that we might like to do home haemodialysis and now I find myself recommending it to others

"There is always someone at the end of a telephone to support us if we have any questions- even in the middle of one Sunday night.

"Home Haemodialysis gives you back your independence."

"Dialysis is now just a minor inconvenience, a bit like the washing up."

If you look on the internet at our web page, www.kidneymatters.co.uk, and click on Patient Information there is a booklet "Haemodialysis at home; the patients' views." Read about some patients' experiences and if you are interested, please contact a Home Haemodialysis team member on 0121 627 5752. They will arrange to visit you at home to check if it is possible, and arrange for you to discuss this with your consultant to see if this treatment is suitable for you.

RENAL RESEARCH AT UNIVERSITY HOSPITAL BIRMINGHAM

The KPA has a long history of raising money for kidney research. Some of you are currently involved in a clinical trial and therefore know a little of the different research studies that are taking place; some of these supported by the KPA. However, there will also be a great number of you who have little knowledge of how the money given is used. This article aims to give an overview of the research taking place at QE renal unit and also to explain a little about research.

In current medical and nursing practice, wherever possible, treatment and care is based upon an evidence base. What this means is that a condition or treatment is researched and the best outcome is selected as the current way to treat.

Most of the QE kidney doctors have an active role in both leading and participating in all types of research. This is both exciting and challenging because doing research properly and well is a time consuming and expensive process. All research is governed by a strict set of rules and guidelines designed primarily to ensure that the patients' rights are protected throughout but also to ensure that each trial collects good quality data that can be relied upon for other clinicians to base their decisions on. This process is managed by the Renal Research Team who work closely with the doctors to manage the many clinical studies.

The UHB clinical trials renal research team has grown over the years and now has 6 nurses, a laboratory technician and a research administrator/ data co-ordinator.

The following is an outline of the type of research and the studies that we are currently involved with. It gives an insight into the range of interests of the kidney doctors at the QE.

Chronic Kidney Disease

We are interested in progressive chronic kidney disease and have started recruiting patients into a large study aiming to find out more about what factors affect the decline in kidney function. This study will recruit 1000 patients and follow them up over 10 years.

Dr Paul Cockwell is leading this study with a big team of nurses, research fellows (Doctors in training), laboratory and administrative staff working with him. This work expands out into the community and we are doing collaborative research with GPs in primary care.

Immune mediated renal disease (for example patients who have vasculitis)

The main doctors leading this work are Professor Lorraine Harper and Dr Matt Morgan. There are several studies running, some of them in collaboration with the Wellcome Trust Clinical Research Facility. There is also a very large programme of laboratory research in this area.

Transplant Research

Drs Simon Ball, Richard Borrows and Adnan Sharif are leading studies investigating some of the more complicated areas of transplantation, including studies that are identifying people at higher risk after transplantation and studies on blood group incompatible transplantation.

Many of the studies we carry out in this area are to do with the drugs that are used in kidney transplantation. Some of these studies are funded and run by drug companies and are important in helping establish the best way to avoid rejection of the kidney and at the same time using drugs that have the least side effects.

Cardiovascular Disease in Chronic Kidney Disease

Patients with kidney disease have many problems associated with heart and blood vessel health. Dr Charlie Ferro works closely with the cardiologists to lead on several studies investigating this area, including studies of treatments to help improve the long-term health prospects of people with kidney disease.

Haemodialysis

The research into this area of kidney failure treatment is now being established. We are looking at different types of dialysers and how they work. We are also working with other kidney units to develop studies examining some of the psychological problems people can have on dialysis. The main doctors working on this research are Drs Colin Hutchison and Clara Day.

Peritoneal Dialysis

We have been collaborating for some years with another unit collecting data on the long-term effects of peritoneal dialysis. Drs Lukas Foggensteiner and Lavanya Kamesh are keen to develop some ideas around this treatment. The unit is also trying to get funding for a study to lower the risk of infections of the exit site for people who are being treated with peritoneal dialysis.

There are also quite a number of other research interests within the unit. Examples are patients who develop kidney problems while they are pregnant (Drs Graham Lipkin and Clara Day) and patients who have inherited disorders (such as polycystic kidney disease).

You can see from the list above how much activity is going on. Some patients get very worried about being invited to take part in a study, but if they do get involved, have often commented on it being a good experience. In the next article I will be outlining how you get to be invited and what it means if you take part in a study.

By Mary Dutton, Senior Renal Research Sister U.H.B.

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

Patient Transport

Patient transport for very many patients is a major problem. The K.P.A. is trying to get a resolution to these issues. We have regular meetings with West Midlands Ambulance Service and U.H.B. and bring to their attention the problems that patients are experiencing. It would help if on every occasion that transport does not meet your needs you write, e-mail or phone the PALs department of West Midlands Ambulance Service .

There are forms and details in every dialysis unit about how to contact them. The phone number is 01384 246370 or 0845 608 0276 or e-mail pals@wmas.nhs.uk. You can email me, flintnf@aol.com if you wish and I will pass on your concerns. The only way we can get improvements to the service is if patients make their concerns known. It does not help if you just tell the duty nurse about the problems.

Patients Holiday September 2012

Staff at the Q.E. are organising a holiday for haemodialysis dialysis patients to visit Rhodes. The dates that are planned are from 15th September to 29th September 2012 staying at the Espirides Beach Hotel in Rhodes. The Hotel is an easy distance from the dialysis unit and there will be staff members from the Q.E. there to support the patients.

This is a very nice resort and patients have been there in the past. If you are interested, please contact Sharon Pilling or Freedom Travel for more details. The details that we have given are provisional at time of going to press, so if you are interested please contact Sharon.

Sharon Pilling 0121 371 3019

Laura Gleadel Freedom Travel 01509 815999

Patients' TV in 301 waiting room.

The K.P.A. has had a television installed in the waiting area of the dialysis unit in ward 301 at the Queen Elizabeth Hospital. The money was donated for this by the family of Bob Smith who sadly passed away. Bob was a very active and former member of the K.P.A.. He was also a Chairman and member the

National Kidney Foundation. Bob worked hard for the benefit of patients. We hope this television will help patients waiting for treatment or are waiting to go home. We thank Bob's sister for supporting the K.P.A. in this way.

World Kidney Day

This year it is on Thursday March 8th. The K.P.A., together with the renal unit at U.H.B., will be having a table in the Renal Outpatients area of the Q.E. There will be patient information and details about the K.P.A. So if you are in clinic on March 8th or on a ward or visiting a relative or friend, why not pop in, have a look and meet us.

Look forward to seeing you all on 8th March

Patient Information

This is a list of patient information booklets that are available . All these titles have been produced by the Hospital for patients. They are available from the Q.E. or you can download and print them off by visiting our website www.kidneymatters.co.uk and go to the section "Patient information".

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

What is the Q.E. Kidney Patients Association	Where will I have my Haemodialysis	Haemodialysis. Having Line removed
Useful Info and Sources of information & Advice	Haemodialysis. Line Insertion	Testing for HIV. Patients with CKD
Healthy Living for people with CKD	Temporary Haemodialysis Away From Home	Going on Holiday. Peritoneal Dialysis
How to Control Phosphate Levels	Risks of having Haemodialysis Abroad	Pre Transplant Information
What is Polycystic Kidney Disease	Haemodialysis at Home - Patients Views	Plasma Exchange
LMBBS Clinic	Common Medication - Haemodialysis	After Transplant information
Urokinase (Syner-Kinase) treatment	Dietary Advice High Potassium ,	Having a Biopsy
Cystinuria Patient Information	Haemodialysis	Peer Support
Conservative Kidney Management	Haemodialysis. Know your Blood Results	Live Donation. Claiming Expenses.
What is Vascular Access	Keeping Health. Reduce infection.	Young Patients. The move from the Childrens Hospital
	Haemodialysis	Young Patient at the Q.E. Youth Worker

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