



# KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. October 2011

Registered Charity No.513446

Visit [www.kidneymatters.co.uk](http://www.kidneymatters.co.uk)

Queen Elizabeth Hospital Kidney Patients' Association

## Young Renal Patients enjoying themselves.

Young renal patients at the Q.E. went on an adventure weekend last month sponsored by the K.P.A.. The Q.E. has a youth worker who works with the younger patients and their move from the Children's Hospital to the Q.E. This is a very daunting and difficult time for them and the help and support that the Q.E. gives them encourages them to move forward. The K.P.A. was able to pay for the adventure weekend due to the ever generous support from patients and carers over recent months and years. This is the second weekend away and it helps the youngsters get to know other patients and meet some of the staff on an informal basis

The weekend was a very enjoyable one with shooting, climbing and rafting to name but a few. As can be seen from the photos, all had a very good time.



## K.P.A. Grand Annual Draw 2012

We have sent out to all patients £5. worth of raffle tickets. The draw takes place on 11th January 2012 at our K.P.A. meeting. Please try and sell these ticket as it is one of our main fundraising events of the year. There are some very good prizes to be won. If you require more tickets please contact Len Ingram on 0121 308 0024, his address is on the back page, or contact any of the committee

Please return the counterfoils and money to the address printed on the ticket counterfoil.



## Friends of the K.P.A. organise a garden party.

Vera Masters decided to organise a garden party to raise funds for the K.P.A.

A summer garden party was held at Ashlawn Crescent on the 24th July. Friends and family very generously brought plants, cakes, refreshments and handicrafts to sell as well as a tombola and "guess the number of spaghetti spirals in a jar"!

A good time was enjoyed by all. Sylvia Goulding and Vera also produced many plants from their gardens which sold very well.

The afternoon raised £417 for the K.P.A. and our thanks go to Vera and all those who helped her.. Thank you.



## Peer support

The peer support programme is slowly but surely embedding itself into the everyday practise of the renal unit. We have now had about a dozen patients use the one to one service all with very positive feedback. Referrals are now picking up as the staff become used to the idea and confident of its success. In addition we have used peer supporters at information days for patients approaching the need for dialysis and the peer supporters are able to provide invaluable insights as to what being on a particular type of dialysis is actually like, or what it's like to have (or even give) a kidney transplant.

This was very successful and will be used as the format for this day moving forward. In addition, some of our younger peer supporters have taken part in the open day for the transition service, which is designed for teenagers transferring across to us from the Children's Hospital. This is a very disconcerting time for young patients and having 'old hands' around to guide and reassure was also very helpful. I am now also hoping to start some peer supporters coming in to see patients on the wards, whether to help with choices about dialysis treatment or just as a friendly face. If you would like to train as a peer supporter, I will probably do some more sessions in the new year. Please do contact me directly at [kidneysupport@uhb.nhs.uk](mailto:kidneysupport@uhb.nhs.uk) or via Nick Flint. This email address can also be used if you would like to refer yourself in to speak to a peer supporter.

Written by Dr Clara Day Consultant U.H.B.

## Fundraising at Sainsbury's Walsall

Thanks to the generosity of Sainsbury's Walsall, the K.P.A. organised a Tombola and collection on Saturday 4<sup>th</sup> June. We raised £576. This has become a bi-annual event and an important part of our fundraising.

Our thanks go to Dawn's mum for gathering an array of prizes

If anyone would like to give prizes for the next Tombola or help on the day for an hour or so, your support would be welcome. Please contact Len Ingram. His details are on the back page. The date for your diary is Saturday December 10th



K.P.A. meetings are held at the (old) Q.E. Hospital on the 2<sup>nd</sup> Wednesday of each month at 8.00 pm in the seminar room (next to the Boardroom).

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



## Family Celebration raises £2615 for the K.P.A.

"On Saturday the 24th of September at The Cross Bar, Moseley, one family - regulars to the kidney unit - hosted the "Prom for Grown-ups" to support the K.P.A.

Over 120 guests arrived via the red carpet in evening dresses & tuxedos ready to party the night away to the tracks of their years. People gave generously and one lucky winner received the star prize from a 'menu' of prizes - a week's holiday to Devon for 6 people staying in a historic barn conversion.

As Saturday became early Sunday the tunes slowed and the revellers heard they had raised a fantastic £2,615, all pledged to the K.P.A.



Vanessa with Mum, Dad, Brother and Niece



Linda & Dave Kirk with Laura Phillips

The Prom fundraiser follows the successful live kidney transplants between two sets of relatives from one extended family. Six years ago this summer Linda Kirk donated to her daughter Laura Phillips and last October Linda's niece Vanessa Cusack donated to her father Robert Green. Vanessa said, "This event was a fun night to celebrate Laura and Dad's good health, but also our family saying 'thank you' to the dedicated staff and volunteers of both the Q.E. and the K.P.A."

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## Longbridge Methodist Church: Year of Fundraising raises £2750 for K.P.A.



Over the last 12 months Longbridge Methodists have been fundraising and decided to donate half of the money raised to the K.P.A. During the year, they had a variety of events which included the annual pantomime Dick Whittington, afternoon cream teas, beauty day, sponsored walks, a dance night and coffee mornings,

All these events raised £2750 for the K.P.A. Everyone worked very hard during the year to achieve this.



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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 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.

## Our Thanks

We have received a number of donations from families and friends of loved ones who have sadly passed away. The K.P.A. extends its deepest sympathy to all the families at these difficult times. Your donations are used to help support patients and the Hospital and we thank you for your generosity at this time.

## Patient Transport :Haemodialysis

Are you using patient transport to get to and from your dialysis session? I would like to hear about your experiences. Is it meeting your requirements? Are you being collected on time? Are you being kept waiting and arriving home late?

I would like to hear from you, tell me about your experiences in the strictest of confidence. You can e-mail me on flintnf@aol.com, call or text 07720597468.

The K.P.A. is working closely with U.H.B. and W.M.A.S to ensure patients receive the best possible service. Please keep us informed so we can do something about it. The figures indicate that the service is improving. We need your feed back to ensure this continues.

Thanks for your co-operation. Together we can make a difference

## Research in dialysis. Dr. Clara Day Renal Consultant U.H.B.

Q.E. renal unit has always been very active in research into kidney disease and transplantation. We have several research studies involving dialysis patients which will be starting over the next few months. Some of these will be asking patients for views on their treatment and why they chose particular dialysis options and research staff will be circulating information about these soon. We will try to carry out studies in your own units and either while you dialyse or just before with taxi transport provided in some of the studies if you would usually travel by transport.

We have much to learn from your experience of your kidney disease and treatment so please do take part if you can!

## 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 web site [www.kidneymatters.co.uk](http://www.kidneymatters.co.uk) and go to the section "Patient information"

More subjects are being added so please keep a look out. If there is a topic you cannot find please, contact the K.P.A. and ask and we will try and find the information you need.

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

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  
Live Donation. Claiming Expenses.  
Young Patients. The move from the Childrens Hospital  
Young Patient at the Q.E. Youth Worker

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