



# KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. October 2015  
Visit [www.kidneymatters.co.uk](http://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, Great Bridge (Tipton), Woodgate, Kings Norton, Smethwick, Sparkhill,  
Worcester, Kidderminster, Hereford, Llandrindod Wells, and U.H.B.

### Gavin shows what can be achieved after a Kidney Transplant



Gavin received a kidney from Darren, his brother-in-law, in 2012 and soon after took up cycling. The following year he represented Great Britain in the World Transplant Games and achieved great success.

This summer he has completed the Coast to Coast cycle ride, 150 miles from Seascale on the West Coast to Whitby on the East Coast, going through the Lake District, Yorkshire Dales, Vale of York and the North Yorkshire Moors. It took 11 hours of cycling and was stunning, although there were lots of hills!

To outdo the rest of the team Darren and 3 of his mates cycled Coast to Coast and back again - 300 miles in 24 hours!

Gavin also cycled in the British Transplant Games in August and achieved a Gold Medal in the Cycling Time Trials.



*This shows what a difference it makes to have a Kidney Transplant and also that the Donor is still able to live life to the full after donation.*

*Well done to both of you, I'm sure this will give encouragement to others who may thinking about donation.*

*Gavin is a supporter of the Queen Elizabeth Hospital Kidney Patients' Association and organises the magazines that the K.P.A. provides on the wards for patients to read.*

*Thanks and keep cycling.*

### Transport update

The consultation by the Birmingham Commissioners has ended. The outcome is not known at this time. I understand that very many Renal Patients voiced their opinions which I hope will help in obtaining a better transport service for patients in the future.

The new contract will not come into effect until the end of 2016 at the earliest. So as the plans develop, I will keep patients informed via this Newsletter or our website.

### Patients on the Transplant Register

*Important notice if you are on the Transplant waiting list.*

Please make sure that the Hospital has your up-to-date phone numbers to contact you. If an organ becomes available, time is all important. If you cannot be contacted quickly you could miss out.

If you have changed your number please phone the Transplant Coordinator on 0121 371 4433



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

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.  
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.**

## Q.E.H.K.P.A. Christmas Draw

With this newsletter there are £5.00 worth of Raffle tickets. We have continued to give cash prizes as we think that is acceptable to all. You will see we have increased the lower prizes but kept the main prizes the same. We hope that patients and friends will support us.

The Queen Elizabeth Hospital Kidney Patients' Association is the **only Renal charity** run by patients for Renal Patients at the Queen Elizabeth Hospital Birmingham. All the money we raise is used for the support of this Hospital and its Renal patients which includes all those who dialyse at any of the Q.E units around the area. This is an annual Raffle and is the

## Gemma Ward

The K.P.A. were very touched by the generous donation of £650. from friends and family in memory of Gemma Ward.



Gemma passed away in April. She was a dialysis patient at the Queen Elizabeth Hospital for over 8 years. During that time she became very popular with the Staff and other patients and offered encouragement and support to many of them.

She will be sadly missed by the Staff and friends she made at the

Queen Elizabeth Hospital.

## Controlling Phosphate

I am sure you have all heard about the importance of controlling phosphate in your diet. This can often be raised in kidney patients. Unfortunately phosphate is mainly found in protein foods which are a very important part of your diet for staying well nourished.

There are a number of ways that by changing the types of protein you eat, you can reduce your phosphate levels within a few days. On our website there is a list of food options to help with this.

Another important issue is taking your phosphate binders correctly. This will also help to keep your phosphate levels under control. There are many different phosphate binders available giving patients more choice of how they prefer to take them – powder, tablets that have to be chewed and tablets that have to be swallowed. The choice of phosphate binder will also depend on other factors such as your calcium level which your doctor and dietitian advise you on.

*There are more details on this subject on our website to help you to keep healthy. All this information is provided by the Renal Dietitians at the Queen Elizabeth Hospital.*

ONLY time we ask all Renal Patients for their support.

We have no paid employees so all the money raised is used for the benefit of the patients, renal research and Hospital.

We hope you will be able to support us again this year as many of you have done in the past. If you would like some extra tickets please contact myself Nick Flint or our Treasurer, Len Ingram, and we will be happy to send them to you. Our contact details are on the tickets and on the back page of this magazine.

Thanks again for your support. The draw will take place on the 13 January 2016 which is the date of our monthly meeting.

*Best of luck to you all and thanks.*

## Improvements in care for HD patients at Q.E.

Over a year ago, following an increase in infection in haemodialysis patients associated with having dialysis catheters fitted, we chose to assess a number of new dressings. As a result of these trials, Q.E.H.B. decided to use Tegaderm Advanced Dressings for all patients. These have given a number of benefits. The dressings remain in place for the full seven days. They protect the patient by lowering the risk of contamination and infection. They also reduced episodes of skin irritation due to reducing the number of dressings used when compared with the previous items.

All Patients with a new dialysis catheter will continue to have the patch applied for the first few weeks until their exit site is healed.

Although we can claim the change has been very successful, we will continue to look for further improvements.

Thank you to all our patients for their support with these changes.

*Liz Simpson Renal Matron Q.E.H.B.*

## Christmas is on its way

With Christmas just round the corner, it will soon be time for planning the festive foods.

For dialysis patients it's a time for careful planning and not missing out on some of the special treats at party time.

The Renal dietitians have put together some diet sheets to help. They cover Festive drinks, party foods and even a Christmas Cake for those on a low potassium diet.

*All these recipes and patient information are on our website [www.kidneymatters.co.uk](http://www.kidneymatters.co.uk) If you are unable to use the internet, if you ask a member of the staff at your unit I'm sure they will print them for you or give me, Nick Flint, a ring and I will send them to you.*

## Message from the K.P.A. Chairman, Nick Flint

I would like to take this opportunity to thank all of you who have supported the K.P.A. this year and over previous years.

I have had the privilege of being Chairman for many years and am always pleased to hear how highly regarded our K.P.A. is with patients. I know how difficult it can be being a renal patient. I spent several years on dialysis and was very fortunate to receive a transplant.

The K.P.A. has very hard working committee members who put a lot of time and effort into running this charity. Without them, it would not be possible to give support to patients and the Hospital.

This year we have been very well supported. The Christmas raffle 2014/15 was very successful and we have had many donations from patients for which we are very grateful. This has also enabled us to continue to support research projects at the Hospital and we have several projects that are being planned.

Last year I spent time working with N.I.C.E.. They were putting together standards for renal treatments, one of which was to improve times for patient transport. This was accepted as a new National Standard last November. This year I have been involved as a patient representative with Birmingham City Commissioners who are developing a new patient transport contract, so I am lobbying for Renal Patients to get a better deal. Renal patients who need transport 6 times per week should have a better service than they receive currently.

We continue to send our Newsletter to over 2200 patients, which I hope you find informative. If you have ideas about what you would like to see in it, please let me know.

Our website gets about 2300 hits a month. If you have not yet had a look, it contains information about treatments and ideas for cooking and eating well on renal diets.

Thank you all again for the support you give to the K.P.A. and I wish you a very happy Christmas and a good New Year.

## Tony Hale supports the K.P.A.

Retired radio presenter Tony Hale offered his services to help raise money for the K.P.A.

Tony has a very interesting and wide range of subjects that he gives talks on. He does this for a wide range of organisations.

This year the Women's Institutes have made organ donation their theme. Tony decided that he would offer his services to the W.I. and donate his fees to the K.P.A.. He has been very successful. He has spoken to many clubs and has bookings for the near future.

*Our thanks to Tony for his support to the K.P.A. and thanks for the funds you have raised.*



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 changing the amount in the message.

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

## Smethwick opens its doors

On June 3rd the first patients arrived to dialyse in a brand new unit. This unit has replaced the unit at City Hospital and over the following weeks all the patients will have moved across.

The K.P.A. with the support of the staff provided some "Welcome Refreshments" for the patients. We must also thank Morrisons who, when it came to paying for some of the food, provided it free of charge. *Thanks Morrisons.*

When I visited the unit and went round and spoke to patients they all said how pleased they were to be in the new unit and that all the staff had made their move very easy. Some said that they were a little nervous about the change but were very relaxed now that it had happened.

## Patient Holiday

Again this year Sharon Pilling has organised a patient holiday. This year it is in Benidorm. They will all be flying off on 23rd September and return on 10th October. We hope they have as good a time as they did last year.

We will have more details about how they get on in the next newsletter.

The K.P.A. thanks Sharon and her staff for giving up their time to help the patients. The Q.E.H.K.P.A. supports this holiday by sponsoring a member of staff.

## 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.

There are now over 50 topics on Patient Information. The booklets are all produced by the Q.E. and are available on our website to download. Just go to [www.kidneymatters.co.uk](http://www.kidneymatters.co.uk) Also you will find lots of information on healthy eating for dialysis patients.

## Research Update:-Vascular Access Project K.P.A. funded last year £23000

Good Vascular Access (VA) is a critical for patients on haemodialysis (HD) but commonly is a source of problems. One problem area is when newly formed fistulas don't mature to a point where they can be used for dialysis. Although it appears from the studies that the results in the UK (and particularly at the QE) are much better than the United States, we still see up to a third of the fistulas we create having problems. We are very keen to try to improve this for patients and have many studies under way at the QE to address some of the problems.

With the support of K.P.A funding we have just completed one of the largest studies ever done in fistula surgery with 200 patients from the QE participating. This study uses a small skin patch which releases a chemical (GTN) through the skin. This has potential to improve the blood flow through the newly formed fistula and may assist in improving outcomes. Results from follow up are still coming through and the effects require analysis. As with all

research studies the strict approach to comparing a treatment with a control, or placebo is necessary to be able to accurately assess a treatment. This allows the benefits of a treatment if they are present to be defined, and also the side effects and disadvantages to be clearly studied. We are grateful to the patients who agreed to take part in the study.

The ability to perform quality research places the QE at the forefront of vascular access provision and new technologies to be made available to patients at an early stage. This study has led to a number of other studies in vascular access which will open opportunities and improve care for patients requiring VA for HD.

The support of the K.P.A is essential to facilitate this research into common problems that affect the majority of dialysis patients at some stage. It is through this research we aim to improve the success of vascular access and improve the patient experience.

**Nick Inston Consultant U.H.B.**

## 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 our support for patients and the Hospital in memory of loved ones.

We remember Gill Moore's Father, Sylvia Leaver, Derek Stroyd and Sandra Eyles.

Our thoughts are with the families at this sad time.

## Recent Donations

The K.P.A. has received donations from Patients and Friends. Some are from fundraising events they have organised. We are extremely grateful to them all for helping us.

Over the last few months we have been supported by Tony Hale, Andy and Jerry Blake and Mrs Showel.

Thank you to everyone who has sent us donations to help with our work. We are very grateful.



## National Transplant Week. 5th–10th September

The Q.E Hospital organised events in the Atrium every day. Each day was focused on different types of transplants and organ donations. Thursday and Friday was about kidney donation. We were encouraging members of the public to sign up for the organ donor register and giving information about organ donation and the benefits it has for patients in need of a transplant.

We met many patients who had received a kidney transplant and heard how it had changed their lives. There were many people who came along who had made a living donation of a kidney, either to a relative or a friend. Several had decided to donate a kidney. It was very encouraging to see and hear how well they were all doing.

We signed up many people to the Donor Register.

*Our thanks to the Kidney Transplant Coordinators for the time and effort they put into organising the week for the benefit of patients.*

<p><b>Chairman/Kidney Matters Editor.</b> Nick Flint 9 Brookhouse Road Walsall, WS5 3AE Tel:- 07720597468 E-Mail Nick.Flint@live.com</p>	<p><b>Secretary</b> Joan Ingram 6 Cremorne Road Sutton Coldfield West Midlands B75 5AW Tel:- 0121 308 0024</p>	<p><b>Treasurer</b> Len Ingram 6 Cremorne Road Sutton Coldfield West Midlands B75 5AW Tel:- 0121 308 0024</p>	<p><b>Vice Chairman</b> Dawn Roach 181 Wolverhampton Road Pelsall Walsall WS3 4AW Tel:- 07533097655</p>
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