

# KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. OCTOBER 2016 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, Great Bridge, Woodgate, Kings Norton, Smethwick, Sparkhill, Redditch, Worcester, Hereford, Llandrindod Wells, and U.H.B.

## K.P.A. Funds Research Project £41000



On the left is Dr. Derek Kyte Lecturer, NIHR fellow, and Deputy Director of the Centre for Patient Reported Outcome Research. Centre, is Mel Calvert Professor of Outcomes Methodology and Director of the Centre for Patient Reported Outcomes Research, both at the University of Birmingham. Receiving the cheque is Paul Cockwell, Professor of Nephrology and Associate Director of Research at the University of Birmingham.

The others are members of the K.P.A.and Staff at the Hospital who are in pink.

The Queen Elizabeth Hospital Kidney Patients' Association is very pleased to be able to support Prof Paul Cockwell and the University of Birmingham in a 2-year research project.

Research is very important to renal patients as this is the way forward to improve treatments and the quality of life for renal patients who face a long time on dialysis. This project is looking at working with patients on dialysis to help them identify what symptoms are most important to them and how they can best report these symptoms to the clinical team.

We are very pleased that the renal patients at the Q.E. have supported the Queen Elizabeth Hospital Kidney Patients' Association so generously by organising fundraising events amongst their friends and families. Patients have done this in many ways: donating money instead of presents on special

occasions; golf days; sponsored bike rides; after dinner speaking; bequests in memoria; donations in lieu of flowers, supporting our Christmas Draw and many more. We also receive many donations and all of these enable us to support the Q.E. Hospital and patients.

Nick Flint Chairman. Queen Elizabeth Hospital Kidney Patients' Association

K.P.A. meetings are held at the Queen Elizabeth Hospital
On the 2<sup>nd</sup> Wednesday of each month at 7.30pm in the 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.



## Tom Simons continues to support the K.P.A.



Tom Simons recently had a kidney from his wife. This year he is supporting the K.P.A. with fundraising events, one of which was with his local Bank, Santander. They organized a "Shirley Bake Off" in their branch and raised £231 and the Bank matched this amount. In the picture is Tom and the Branch Manager and Area Manager presenting the cheque to us.

Tom has organized several other fundraising events during his year to raise money for us before his year as Captain of Shirley Golf Club comes to an end in November.

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

With this newsletter there is one book of raffle tickets worth £5.00. We have continued to give cash prizes as we think that is acceptable to all. The first prize is £300. and there are 12 other cash prizes. We hope that you and your friends will support us in this fundraising project.

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 11 Q.E units around the area or at home. This is an annual raffle and is the ONLY time we ask all Renal Patients for their support. We hope you will support us with this. We know you will receive many requests to support renal charities, but this is the only one that is for the benefit of the Queen Elizabeth Hospital and its renal patients.

We have no paid staff or expensive offices, so all the money raised is used for the benefit of the patients, renal research and the 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.

Last year's raffle raised over £3500 which enabled us to continue our support with the projects you read about in our magazine. The draw will take place on the 11 January 2017 which is the date of our monthly meeting.

Thanks again for your support.

Best of luck to you all and thanks.

## Transplant Week at Q.E.



The first week in September was National Transplant Week. At the Q.E each day was dedicated to either Kidney, Heart, Liver, and Lung transplant. The Renal Transplant Team together with the K.P.A. were in the Atrium on two days signing up people to the



organ donor register and answering questions about donations and

living donations. The public were very interested and very many signed up.

Members of staff from the transplant coordination team were on hand to talk to the public about organ donation. It was a very worthwhile event and promoted the work the Hospital does as a major transplant unit.

## Kidney Transplant patients Gavin and Simon "Rule the Roost"



Earlier this year Gavin Giles and Simon Batch, both kidney transplant patients, were competing in cycling championships. Gavin was in the Transplant and Dialysis Sports Championship in the European Games, winning a bronze in the cycling time trial. Just 2.6 seconds separated 1<sup>st</sup> and 3<sup>rd</sup>! Gavin said "I was really happy with my time as it puts me in with a chance at the World Transplant Games next year."

We wish him well for that event.

In July, it was the British Transplant Games and Queen Elizabeth Kidneys "ruled the roost" in cycling again. Gavin won gold in the time trial, and was outright winner, and Simon Batch won the gold medal and was overall winner of the road race. Gavin said" Some turn around for both of us considering where we were 6 years ago before our transplant".

In August Gavin also cycled 210 miles from Innsbruck to Lake Garda through the Austrian and Italian Alps over 2 1/2 days. It was on the Euregiotour which is organised to raise awareness of organ transplantation. Over 100 cyclists

took part with 40 of those being transplant recipients.

This is a remarkable achievement for both of them and is a great example of how life changing a kidney transplant can be. Well done and keep bringing back the medals.

## Patients enjoy outings to the coast

Patients from Aston and Redditch dialysis units enjoyed a day



out at the coast. Staff at Redditch organised a trip to West Super-mare in August. They had a very enjoyable day out and the weather was very good.

In September a member of staff organised two coaches to take Aston patients to Scarborough for the day. It was a good day out and patients had a wonderful time.

These days out are very beneficial to patients as many would not be able to do them on their own. It is very generous of



the staff to give up their time to help and support patients. The K.P.A. was pleased to be able to help towards the cost of the trips, again through the very generous support of patients.

Don't forget if other units want to organise similar events

the K.P.A. will look at how we can help.



## **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.

### **Patient Information**

There are over 50 topics on Patient Information covering all areas of renal care, pre dialysis, different types of dialysis, transplantation, organ donation, living with renal conditions. The booklets are all produced by the Queen Elizabeth Hospital. and are available on our website to download. Just go to www.kidneymatters.co.uk

Also on our web site you will find lots of information on healthy eating for dialysis patients. All the information is from the renal Dietitians at the Queen Elizabeth Hospital. For more dietary information, contact your unit dietitian. If you don't find what you need please ask at your clinic or dialysis centre.

## **Donations**

We would like to thank all those who have supported the K.P.A. recently with donations. Tony Hale has been giving after dinner talks to organisations, W.I. Groups, Gardening clubs and many others and has very generously donated his fees to us. Over recent years this has been several hundreds of pounds.

We have had donations from a birthday party for Ray Bodfish. Two very generous patients have set up direct debits; a local Café in Lichfield has a collecting tin on their counter and Lloyds Bank donated £500 to support Tom Simons Golfing Year. Cindy Rogers had a "Dress Down Day", The Rotary Club of Brownhills; the Rodway family; Angela Vickers and Wilo UK. Ltd.,

Thanks to you all for your generous donations.

We are very grateful to all who help and support us as this enables us to continue to support patients and the Hospital that looks after us all so well.

#### Friends and Family Test or F.F.T.

This is a phrase that most of you will have heard about but have you filled a form in? It's one of the ways the Hospital finds out about what the patients think about their visits to the Hospital for their treatment or their clinic appointment.

#### Please complete the Friends and Family Test (FFT)

The FFT is a quick easy way to give valuable feedback about the care and services provided by University Hospitals Birmingham NHS Foundation Trust. It helps staff understand what they are doing well, and where improvements are needed. Your views are important and are greatly appreciated.

You can complete the NHS Friends and Family Test (FFT) whilst you are on the ward via the bedside television or hand-held computer tablet (ask staff for details).

If you are visiting as an outpatient, the FFT is available on the self-check-in kiosks in outpatients, via a comment card that can be found in the outpatient department or on the Trust website. If you are attending for dialysis the cards should be available in all dialysis units – please ask staff if they are not visible.

If you attend the Emergency Department, you can complete the FFT either by comment card as you leave the department, or by SMS text if contacted (all texts are free). Lots of improvements have been made following feedback given via the Friends and Family Test...your comments really do make a difference!

#### 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, Phil Ayres, Mrs. Bessie Rickard, Vera Harris, Dean James Wright, George Jones, Vera Hands, Dave Davies.

Our thoughts are with the families at this sad time.

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.

#### Do you still wish to receive this newsletter?

If you **DO NOT** wish to receive this newsletter, please let us know by contacting:-Lorraine Bateman. Tel: 0121 371 4957 Email. Lorraine.Bateman@uhb.nhs.uk

OR complete the section below and return to:-

Lorraine Bateman. University Hospital Birmingham NHS Foundation Trust, Room 43F, 4<sup>th</sup> Floor Nuffield House, Mindelsohn Way, Edgbaston, Birmingham B15 2TH

My Name......Address...

Post Code.....

Please remove me from the mailing list, I no longer wish to receive this newsletter

If you are transferring your treatment away from the Q.E you will be taken off
the mailing list automatically.

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