



# KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. FEBRUARY 2017  
**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, Woodgate, Kings Norton, Smethwick, Sparkhill, Redditch, Worcester, Hereford, Llandrindod Wells, and U.H.B.

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### Football Club Raised £2000 in Memory of former Member



*In the picture is Club member Geoff.Bembow (right)and Len Ingram from the Queen Elizabeth Hospital Kidney Patients' Association receiving the cheque for £2000*

Ray Coley was a long time member and supporter of Bustleholm Football Club West Bromwich. He was a renal patient for many years but sadly passed away last May. Ray was a very active member of the Club which runs several teams for all ages and he helped encourage youngsters.

Members of the club decided to raise some money to support the Hospital and the renal patients. They started with a charity football match and then had various events during the year. In total, they raised £2000 which they presented to the Queen Elizabeth Hospital Kidney Patients' Association.

This will to help us continue supporting the hospital and renal patients.

We thank them for their support and congratulate them in the work they are doing for young people.

### Siddhartha Bandyopadhyay (Sid) organised a Tennis Competition

Sid, a renal patient at the Q.E. contacted the Queen Elizabeth Hospital Kidney Patients' Association last year with an idea to raise some money for the Q.E.H.K.P.A.

He organised a One Day Tennis Competition at Edgbaston Tennis Club in November 2016. His target was to raise £1000. Sid finally raised an amazing £2000 thanks to all the support from friends, colleagues and family. This was a very successful event and Sid was delighted with the amount raised.

The Q.E.H.K.P.A. would like to thank Sid and all those who supported him.



### Q.E.H.K.P.A. funded Research Nurse

Following on from the generous funding by the Q.E.H.K.P.A. for a Renal Research nurse to undertake research in the University of Birmingham Centre for Patient Reported Outcomes. We have now appointed Nicola Anderson to this post. Nic embarked on a 2 year part time Masters Degree in October 2016. She will be researching using Patient Reported Outcome measures (PROMs) to promote quality of care and safety in the management of patients with end stage renal disease requiring treatment with haemodialysis.

She will be working with a patient advisory group to develop the PROMs, looking at which outcomes and measures would be acceptable to both patients and clinicians. The work will also look at the detail around best timing for monitoring PROMs and also the best way of using them – for example – do people prefer electronic ways of communicating, using the phone or sending in paper forms.

Nic is currently signed up to many academic courses in the University department so that her work will be fully informed. She is fortunate to be working with a great team who are already working with the Q.E. renal unit looking at PROMs and its uses in patients with chronic long term kidney disease.

*Mary Dutton Senior Nurse, Renal Research UHB.*

## Q.E.H.K.P.A. Chairman receives Award



A surprised Chairman of the Queen Elizabeth Hospital Kidney Patients' Association, Nick Flint, was awarded UHB's Member of the Year at the Best of Care Awards held at the Tally-Ho in November.

Nick underwent a kidney transplant himself 18 years ago and has worked tirelessly ever since to improve the lives of those patients with chronic renal failure for many years.

He works behind the scenes for you in many ways and is often seen in the dialysis units checking on the services and raising issues with the Q.E. and the dialysis companies. He is a peer supporter and takes phone calls from patients who need a friendly ear.

As Chairman of the Q.E.H.K.P.A. committee Nick is known to man stalls in the Atrium to raise awareness about kidney matters to staff and visitors and puts together this newsletter for patients. He also works as a patient representative in various projects to improve patient care in the region and works very hard to keep renal patients' interests to the fore. His passion for supporting renal patients has resulted in the Q.E.H.K.P.A. raising many thousands of pounds for projects to help patients and the Queen Elizabeth Hospital.



## Update on The New Patient Transport Service

West Midlands Ambulance Service NHS Foundation Trust (WMAS) has been awarded a five-year contract to deliver a new non-emergency patient transport (NEPT) service for around 8,500 patients a week from 1 May 2017. NEPT services are for people that have a medical need, and require specialist assistance to travel to or from NHS services. The service plays a critical role in patient care and the CCGs are investing in the new service to ensure patients receive a high quality, safe and timely service.

By investing in this new service the CCGs, working with WMAS, will deliver a range of improvements for patients:

- Central booking hub, providing travel advice for patients who apply but are not eligible for free transport
- Give patients the option to sign-up for real time information alerts to track the status of their NEPT journey request
- Give patients the option to provide patient feedback after each journey via SMS text message or email
- A new patient charter, which will provide information on response times and what patients can expect

- Access to a wide range of ambulance vehicles to meet the medical needs of patients, including high dependency and bariatric patients
- Specially trained staff to ensure patients receive the best possible care and are sympathetic to their needs
- WMAS has invested in a specially designed fleet of vehicles that include the latest technology to provide real time information and journey status to patients
- Brand new strategically placed operating sites that bring real benefits to staff and the communities that they serve
- An increase in staff numbers, which will create jobs in the area and provide better services to patients.
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The new patients charter will be published in May 2017 when the service is launched.

*We look forward to a new service meeting our needs.*

## This Year's Patient Holiday

Plans are being made for another patient holiday later this year. There is a possibility it will be to Greece. This is a great opportunity to take a holiday particularly if you have not been away on dialysis before.

If you are interested in going please contact Sharon Pilling. If you are at one of the satellite units, ask a member of the staff to pass on your details to Sharon and she will keep you informed.

Sharon is based at the Q.E. Hospital on ward 301





## Research Project at Q.E.for Renal patients with multiple diseases. The 100,000 Genomes Project

Queen Elizabeth Hospital Birmingham (QEHB) patients with a number of renal diseases may be eligible to take part in the pioneering 100,000 Genomes Project.

The ambitious NHS England initiative aims to improve understanding, diagnosis and treatment of rare diseases and cancers by collecting and decoding 100,000 human genomes – complete sets of people's genes – paving the way for personalised treatment.

Patients with certain cancers and those with an eligible rare disease plus their families are being recruited via 13 Genomic Medicine Centres covering the whole of England.

University Hospitals Birmingham U.H.B. NHS Foundation Trust, which runs QEHB, is leading the West Midlands Genomic Medicine centre (WMGMC) – a collaboration of 18 NHS Trusts delivering the project across the region.

Renal conditions currently eligible for inclusion are:

- Renal cancer
- Proteinuric renal disease
- Familial haematuria
- Atypical haemolytic uraemic syndrome
- Cystic kidney disease
- Congenital Anomaly of the Kidneys and Urinary Tract (CAKUT)
- Renal tubular acidosis
- Renal tract calcification (or Nephrolithiasis or nephrocalcinosis)
- Extreme early-onset hypertension
- Unexplained kidney failure in young people

For more information speak to your clinicians at QEHB, call the WMGMC team on 0121 371 4821, email [wmgmc@nhs.net](mailto:wmgmc@nhs.net) or visit [www.westmidsgmc.nhs.uk](http://www.westmidsgmc.nhs.uk).

## Christmas Draw Winner 2016/2017

Winners name	Ticket no	Prize	Winners name	Ticket no	Prize
M Sheasby	07392	£300	A Akhter	22520	£25
R Cheeseman	23564	£150	S Pearsall	07568	£10
A Hamod	17981	£75	E Davies	24726	£10
M Groom	09683	£25	C Brannon	03234	£10
R Bates	13198	£25	C Syntichatis	11194	£10
A Hughes	14014	£25	L Smith	03844	£10
Young	19536	£25			



The thirteen lucky winners of this year's raffle have all been notified of their winnings.

The K.P.A. would like to thank all those very generous people who supported us this year. We raised £3186.50. It was a superb effort.

The draw took place at our January meeting and Renal Sister Karen Tullett drew the winning tickets.

All the money we raise will be 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, those at home and CAPD. This is an annual raffle and is the ONLY time we ask all Renal Patients for their support.

We thank you for supporting us this year. 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.

## Donations Received

We would like to thank all those who have supported the Q.E.H.K.P.A. recently with donations.

Tony Hale has continued to support us with his after dinner talks; Transplant Week, Atrium £139; Penkridge Rotary £500; Jeremy Duggan £100; Schola Warwiciensis £75; Jenny Gillies organised an Art Exhibition £86.27; Nigel Matthews Celebration £30; Pauline Bedhall £100; High View Residents £250; Vera Masters Christmas Handicrafts £200; SSP Ltd. Staff donations £208.95 and also Ian Brown donated biscuits, chocolates and shopping vouchers.

We also acknowledge the numerous donations received with the Raffle. There are too many to respond to individually but thank you all for your thoughts, comments and generosity. 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.

## News from the Q.E.H.K.P.A.

What has the Q.E.H.K.P.A. been up to?

Quite a lot has happened since the last Newsletter. Christmas is a busy time for all and we've been trying to help in different ways.

The Renal Dietitians asked if we could fund and produce some festive diet sheets for them to give out to patients. We hope some of you read them and found them useful. They included a delicious low potassium Christmas cake which would be suitable for any celebration at other time of the year. There were also party menus and suggestions for menus. Copies of these are all available on our web site for you to download.

We funded the Christmas Hampers for those in Hospital over Christmas and the Christmas decorations on the Renal Wards with the help of U.H.B. Charities. Again we bought mince pies for the patients on the renal wards.

The Q.E.H.K.P.A. also supported the dialysis units that organized parties or outings at Christmas.

The Q.E.H.K.P.A's next event is World Kidney Day on March 9<sup>th</sup>. We will be supporting and promoting renal services the theme is "Healthy Life Style and Health Living" This will be in the Atrium of the Q.E. Please come along and have a look or join us on the day.

We are also planning a Tin Collection and Tombola at Tesco's Walsall. The date has not been finalized but will be in June this year. Details will be on our web page. Any support would be appreciated.

The Q.E.H.K.P.A. will also be involved with the developments in the new patient transport contract and ensuring renal patients' views are listened to and their needs met.

If you would like more information about the K.P.A. please contact us or join us at our monthly meetings.

## Donating to the Q.E.H.K.P.A.

The Q.E.H.K.P.A. now has two links on our web page to make it easier for anyone wishing to donate or raise money for the Q.E.H.K.P.A. One is with PayPal which enables anyone who wishes to make a donation to us by credit card can do so by going on our web page and donate.

The other is using 'My Donate'. Anyone can make a donation to the Q.E.H.K.P.A. or set up a fundraising event and encourage friends to support you. This is a very simple way to organise a sponsored event. Just go to our web page and donations and set up an event.

Go to our web page and have a look.

Hope you can support us. Thank you.

Q.E.H.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 website or phone a committee member in case of a change of date of the meeting.

**EVERYONE IS WELCOME.**

**SUPPORT YOUR Q.E.H.K.P.A.**

## 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, Colin Edwards, David Wilkins, Lalit Tholoj, Pastor Patrick Adetuivo, Mrs Margaret Jessie Shaw, Evan Pritchard, Terence Leonard Westwood, John Sheaf and Ray Coley

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 to 70070** 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.

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

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

☐ No longer a patient at Q.E.

☐ Please do not send

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