



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. February 2014
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, Tipton, Woodgate, Kings Norton, City, Sparkhill, Lichfield,
Worcester, Kidderminster, Hereford, Llandrindod Wells, and U.H.B.,

K.P.A. Christmas Draw.



The Christmas Draw was a great success. We have raised £3469.10. We would like to thank all those who supported us again this year. Special thanks to Mr Patel who is our record sales supporter and sold £410 worth of tickets. This is the 3rd year running he has supported us in this way.

We would also like to thank those who chose not to buy tickets but sent us very generous donations.

The picture is at the January meeting when the lucky winners were drawn. All the winners have been contacted. A full list of the numbers is on the back of this Newsletter and also on our web site.

Thanks again for all the support.

Bequest from Ms.M.E.Downes.

We are very pleased the K.P.A. has been given £55000. This money has been handed over to the Queen Elizabeth Hospital Kidney Patients' Association to help us continue our support for Renal Patients and the Renal Department of The Q.E. Hospital.

We will now be looking at a range of projects that we can support which will benefit all renal patients, whilst respecting the wishes of Ms. M.E. Downes who made the original bequest.

We wish to thank Mr Hing of Mundy's, Lawyers in Hereford, for his part in enabling this to happen.

Anonymous Donation of £10,000

The K.P.A. was very pleased to receive a letter recently informing us that we were to receive a donation of £10,000 to be used by the K.P.A. for Renal Research projects. The person who made the donation wishes to remain anonymous.

The K.P.A. would like to thank them very much for this donation. We have some projects in mind and have been talking to the Q.E. Hospital Renal Research Department about how this can be used.

WiFi on 301

I am very pleased to report that WiFi will be available to patients on ward 301 from February 2014. It will be available free of charge for a 3 month trial period. During this time we will be seeing how patients use it and if they find it an advantage to them. You will be able to access Internet, Catchup TV, send and receive emails, all the usual things you do on computers. You will need to bring in suitable equipment i.e. Tablets, laptops, android phones etc. Passwords will be supplied by the staff.

I hope you will find this an advantage and enjoy being able to use it during treatment.

I would like your feedback on how you find this service, so that changes can be made if needed. The long term plan is that Wifi will be available in all wards in the Hospital but possibly at a charge. The K.P.A. wants the Renal Area to be a special case and we will be endeavouring to see that Renal Patients have free access. This may mean that the K.P.A. subsidises the service from our funds.

Enjoy using Wifi. Your comments would be appreciated.
Nick Flint Email:- flintnf@aol.com

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
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..

Barbara organised a Hair Raising Event



We organised the event in order to raise money and awareness of kidney related illnesses. My mother, (left in the picture) has stage 5 kidney failure and is on dialysis.

The Station Pub and all the staff have been wonderful in helping me raise money for this great cause and raising the profile of the charity.

We had a band called '360' play a live set on the 1st November at The Station Pub. On this night one of my good friends, and supervisors of the venue Ema-Louise Thornton (centre), had her ponytail cut off in an auction and then had her hair shaved for the nights events. The hair has been sent to The Little Princess Trust to make a wig for a child with cancer.

These charities are very close to mine and my families hearts and we are all so unbelievably grateful and happy that it's been such a success!

Half of the money will go to the B.K.P.A. to be used to help families with loved ones going through kidney illnesses have more support. The other half will go the Queen Elizabeth Hospital Kidney Patients' Association to help make patients' time there feel more comfortable, and also help young renal patients as they move from The Children's Hospital to the Queen Elizabeth Hospital. The event raised a total of £2276.

I would personally like to give a huge thanks to:

Ema-Louise Thornton, Kevin Moore, 360, Keith Ward, Mark Degenetais, Russell Howard and everyone who has donated and shown support through The Station Pub and The Comedy Junction!

Barbara Gonzalez-Jaspe

Doreen Lewis

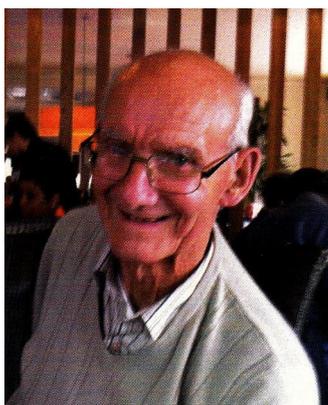
It is with great sadness we have to announce the death of Doreen Lewis on the 26th September at the age of 69.

Doreen had been a kidney transplant patient since 1977. 36 years is a real achievement. She was a very active member of the K.P.A. until quite recently when ill health prevented her from taking an active part.

In the early days she participated in the Transplant Games and was the Treasurer at one time.

Doreen enjoyed many holidays with the Donor Bus, helping Bill Essex (former Transplant Co-ordinator at the Q.E.) organise numerous trips, including five visits to Belgium and Jersey.

She was a great friend and lovely lady and will be greatly missed by all.



David Rodgers

It was very sad that over Christmas one of our committee members passed away.

Mr David Rodgers (age 84) had been ill for some time. David had been a committed supporter of the K.P.A., regularly turning out for our fundraising events despite not being well. We will miss him dearly at our meetings. We send our deepest sympathies to his wife Ivy and the rest of his family.

David was a real gentleman.

In Memoriam

The K.P.A. would like to thank all friends and families who have made donations to us in memory of loved ones. These include John Cooper, Kathleen Paine, Eric Powell, Kathleen Hoskins and Michael Beech, Our sympathies from the Q.E.H.K.P. go to the families.

Vera Masters supports the K.P.A. at Christmas

Christmas time and Vera is hard at work again supporting the K.P.A.. Vera organised two Handicraft events before Christmas. She made lots of nice things for Christmas and with tremendous support from friends and family has raised £620 for the K.P.A. A BIG THANK YOU to Vera and all those who helped.

Vera has been supporting the K.P.A. on a regular basis for a number of years at Christmas time and in the summer with a garden fête.

Thanks and very well done.

First Home Haemodialysis Christmas party



Home Haemodialysis at The Queen Elizabeth Hospital has been steadily growing over the years. We now have a total of 55 patients dialyzing at home with the support of their carers, nursing and medical team.

Saturday 30th November 2013 saw the QEHB Home Haemodialysis Department hold their first ever Patient and Carer Christmas Party. The event was organised by Home Haemodialysis patient, Neil Marklew. "I organised this event to bring patients, their carers and the wonderful staff who look after us and make it possible to do this demanding treatment at home, come together in a social environment. This is important to some patients as they miss the camaraderie and banter at a unit based treatment centre" said Neil

The event was jointly funded by QEHB Kidney Patients Association (QEHKPA), Gambro and B Braun. Thanks to their very kind donations those who attended enjoyed a 3 course meal and danced the night away to the tunes of the resident DJ provided by The Ramada Hotel Oldbury. "We had a very

good turnout, and a great night was had by all" said Neil.

"It's fair to say we all had a great time. Patients, carers, nurses, consultant and technicians all enjoying the first Christmas party. Seeing everybody together as one group is great especially away from the hospital setting." said Colette Doyle, Home Haemodialysis Nurse Specialist.

Carer, Pam Parkes added "Ken and I would like to thank the QEHD for a lovely evening on Saturday. We both had a super time - it's the first time I've seen Ken on the dance floor for over 2 years! We really appreciate all the time effort and hard work that was put in to making Saturday such a huge success. "

Following this positive response Neil is hoping to organise another event in the summer of 2014.

Patients on Anti-rejection medication.

As from April 2014 the NHS has proposed that all Anti-rejection medication will have to be prescribed by, and collected from the Hospital and not from your G.P. This will cause concern amongst transplant patients.

A statement from the Q.E.:-

The QE recognises that patients are worried about what will be happening with regards to prescription of your transplant medication from April when it is proposed that all transplant anti-rejection drugs come from the hospital and not the GP. We are working hard on agreeing a solution with primary care that will be straightforward for patients and ensure that it is easy for you to get hold of your

medication. We hope that this will not require any extra visits to the hospital for you.

There is at present a lot of confusion in primary care because there has been conflicting advice. In the meantime, if patients find that their GPs suddenly stop providing medication, please be in touch immediately with renal outpatients on 0121 371 5633 and we will provide you with your drugs

Simon Ball, Consultant U.H.B.

The K.P.A. will be following these developments closely and keeping the patients' interests paramount. If anyone has any problems please make contact with the Hospital who will provide the medication.

Queen Elizabeth Hospital Kidney Patients' Association.

News from around the area

- We were very pleased to hear from a transplant patient in Tamworth, Clare Edmonds. She successfully received a kidney from her sister 14 years ago and now both have little boys aged 4 and 3.
- The K.P.A. provided funds to the dialysis units for Christmas buffets on, Ward 301, Aston, Tipton, Sparkhill, LLandrindod-Wells, City, Hereford, and Kings Norton.
- Dave Davis, with support from Fresenius organized a Christmas party for dialysis patients at the Tally Ho Restaurant.

• Patients at Hereford Unit enjoyed a trip to the local theatre to see a pantomime.

• Two members of the staff at the Q.E. decided to make knitted badges. They raised over £200 and gave half to the K.P.A. . Thank you both very much.

• We were very pleased to receive a donation of £100 from Bev Matthews, Her husband received a kidney transplant from a friend just before Christmas. From the sale of Christmas Cards Bev raised £100. for the K.P.A..

Thank you

Q.E.H.K.P.A. Tombola at Sainsbury's

Thank you to Sainsbury's customers for generously supporting our tombola and collection at the Walsall store on 25th January. We raised £360. Thanks also to Sainsbury's for allowing us to fundraise there.

We will be back in the summer and if any of our K.P.A. supporters can help by joining us for an hour or two please ring a Committee member. The phone numbers are on the back page and we can add you to our rota.

Thanks to all those who helped with the collection on the day. Special thanks to Dawn's Mum who helped with all the prizes.



Would you like to help save lives?

Are you from the Pakistani or Mirpuri Muslim community?

A new project, focusing on raising awareness of how donating an organ, blood or bone marrow can make real changes to many lives is being coordinated by national charity, Kidney Research UK, working with Dr Adnan Sharif, Consultant Kidney Doctor at the QE hospital.

Dr Shariff says: "It is well known that there are a disproportionately **high** number of patients from this community who are waiting for life saving and life enhancing treatment and transplants. However, it is also well known, that there are disproportionately **few** donors from this community".

This Department of Health funded project is aimed at training people from the community to become champions - called Peer Educators - and to raise

awareness of these issues within their community and encourage people to sign up.

We really need YOUR help to help the Peer Educators raise awareness and get into the community – to mosques, community centres, colleges, and events – ANYWHERE & EVERYWHERE where the community gathers.....do YOU know where they could go to reach the community and raise much needed awareness, and can you facilitate that access please?

If you can help and to find out more, please contact Project Manager, Neerja Jain on 01923 510 196 or 07810 555 844 or email: neerjajain@kidneyresearchuk.org
THANK YOU!

World Kidney Day

This year it is on Thursday 13th March. The K.P.A. will be organising a Renal Awareness Day in the Atrium of the Queen Elizabeth Hospital from 9.30 until 4.00pm

We will have information about the K.P.A. and the services of the Renal unit at the Hospital. If you are in the area that day please pop and meet us.

If any patients or Carers would like to come and help us on the day please contact one of the committee members. Details are on the back page.

Hope to see you on the day.

Pathway by Juliana Wey

Juliana has written and published her story. It is an autobiography of her life's journey and her struggle to deal with her life and the problems she has had to deal with.

"Pathway deals with reality and has a clear message. This book will come as a breath of fresh air for those who are facing difficulty."

Available from Amazon.

Winning Numbers Christmas Draw 2013/14

NAME	TICKET NO	PRIZE	NAME	TICKET NO	PRIZE
G.BENNETT	8075	£300	M.PATEL	8562	£10
T.CHEESEMAN	16602	£150	L.COPSON	19452	£10
C.MEDDINGS	20894	£75	R.PRICE	18689	£5
T.MISTRY	8591	£10	J.SINGE	1280	£5
T.SMITH	14449	£10	R.STANTON	17594	£5
T.PATEL	8887	£10	D.BULL	22050	£5
V.HANDS	7256	£10			

The K.P.P. thanks all those who supported the raffle this year and congratulations to all the winners.
We raised £3469.10.

Thanks again to all.

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 just changing the amount in the message.

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

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