



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. February 2018
VISIT www.kidneymatters.co.uk

Registered Charity No 513446

Queen Elizabeth Hospital Kidney Patients' Association

The Patients' Association is 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.

Kidney Matters is distributed free to over 2500 patients treated by the Q.E. Hospital

1968-2018 Celebrating 50 years of Kidney Transplants at the Queen Elizabeth Hospital

The Q.E.H.K.P.A. congratulates and thanks all the team
of the
Queen Elizabeth Hospital Renal Unit for this outstanding achievement.

Over the 50 years so many lives have been changed. The "Gift of Life" to so many is due to the dedication and care from all the staff involved. Not only has it changed the lives of those who have been fortunate to have had a kidney transplant but it gives hope to those who are waiting for one. Currently there are about 850 patients at the Q.E. who have had a kidney transplant. There are many more who had a transplant at the Q.E but are now living and being treated in other parts of the country. The Q.E. has carried out 4156 kidney transplants plus 994 living donor transplants in 50 years, so this year will also see the 5000th transplant and the 1000th living donor transplant. *What an achievement.*

At this time of celebration, one must never forget the generosity of all those who were the donors and their families who at a very sad and distressing time agreed to allow their organs to be used to help others.

Andrew Ready: How it all started at the Q.E.

The first transplant took place in May 1968. This was followed by further cases during that year. My predecessor, Tony Barnes, was the lead surgeon in this programme, but he was supported by his seniors at that time. These included Professor Frank Ashton, Professor Geoffrey Slaney (who was to become the President of the Royal College of Surgeons and was subsequently Knighted), and Mr. Paul Dawson-Edwards, who had been a Research Fellow at the Brigham and Women's Hospital in Boston U.S. of A. where the very first transplants had been performed. It is my understanding that Paul Dawson-Edwards continued to have friendship with the Nobel Laureates at Boston, but did not continue in the transplant programme at Birmingham, preferring to develop a career in urology.

Sadly, all these people are now deceased including Tony Barnes, who died in 2016. I had the privilege of being House Officer and Registrar to Frank Ashton and Geoff Slaney, knew Paul Dawson-Edwards slightly and was Registrar, Senior Registrar, and a Consultant colleague to Tony Barnes. I think it would be accurate to say that they were all exceptional individuals.

Andrew Ready MBE, Consultant Transplant Surgeon, Queen Elizabeth Hospital Birmingham

Andrew Ready receives an MBE



A very well-known name to many of us, Mr Andrew Ready, Consultant Transplant Surgeon, at the Q.E. was recognised for his outstanding work in transplantation with an MBE in the New Year's Honours list.

Mr Ready joined the Q.E. in 1995 as a Renal Transplant Surgeon. Not only has he done outstanding work at the Q.E., he has played a major role in developing renal transplantation in the developing world. He is also Medical Director of a charity that is dedicated to support renal transplantation in the developing world and has taken voluntary teams to Ghana, Nigeria, Trinidad, Jamaica, Barbados and Nepal to undertake kidney transplants and to pass on his knowledge to Doctors and Surgeons in those countries.

Congratulations and very much deserved. Q.E.H.K.P.A.

World Kidney Day, Thursday 8 March

The K.P.A. and members of the Renal Team will be in the Atrium of the Q.E. to mark World Kidney Day. We will also be celebrating 50 years since the first Kidney transplant at the Q.E.

We would like to mark the day and the year by inviting transplant patients to send in to us a brief story about how their transplant has changed their lives, what it meant to you or how you felt. Please include a photo if you wish and contact details. We will put these up on a wall board to be shared on the day and then post them all on our web site. We will of course remove names to protect people's privacy, if you so wish. Please send them in before March 6th.

It would be good to meet patients on the day so, if you can spare the time, pop along and meet your K.P.A. and members of the Renal Team.

Q.E.H.K.P.A. Annual Draw 2018



The K.P.A. would like to thank all those very generous people who supported us this year. We raised £3387. It was a superb effort.

The draw took place at our January meeting and Jay Nath and Kam Patel, Transplant Surgeons, drew the winning tickets.

All the money we raised will be used for the support of the renal patients and the Hospital Renal Unit. This includes all those who dialyse at any of the 11 Q.E. dialysis units around the area, those at home and on CAPD.

This is an annual raffle and is the ONLY time we directly ask all Renal Patients for their support.

The K.P.A. thank all those who very generously sent a donation along with the raffle tickets. We also thank Mr C. Patel who sold £180 worth of tickets. We received many letters of thanks and appreciation for the work we do and that of the Hospital.

We thank you for supporting us this year. We know you will receive many requests to support other renal charities, but this one is for the benefit of Renal patients and the Queen Elizabeth Hospital Renal Department.

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

Winners name	Ticket no	Prize	Winners name	Ticket no	Prize
M. McNeill	07700	£300	R. Smith	00924	£25
S. Asthana	10885	£150	T. Evans	00907	£10
S. Meghan	03864	£75	Madan Lai	10572	£10
N. Devi	05320	£25	F. Lemm	06375	£10
M. Chopra	10999	£25	C. Evans	14308	£10
B. Bhatt	00234	£25	P. Frazier	12265	£10
M. Forrester	13838	£25			

Hospital Travel Costs Scheme.

The Hospital Travel Costs Scheme, may be of help and interest.

If you are on any one of the benefits listed below you are entitled to claim for the travelling costs to attend your Hospital and or dialysis appointments.

The claim forms are available at your dialysis unit or the Cashier's Office at the Q.E. on the ground floor, near Renal Outpatients.

The travel costs cover, bus, train and parking and also taxi if your clinician considers it's necessary due to your medical condition.

These are the benefits you need to be receiving to be eligible: -

Income Support, Income Bases, Employment Support Allowance, Income Based Job Seekers Allowance, Low income, HC2 or HC3 Certificate, Tax Credits with exemption cert, Pension Credit Guarantee Credit, Universal Credit.

For more information, ask for the forms or phone the Cashier's Office 0121 371 5367 or contact the K.P.A.

Patient Information

If you go on the Q.E.H.K.P.A. Web site www.kidneymatters.co.uk you will find copies of all the U.H.B. Renal patient information. They cover the different types of dialysis, information on treatments and all about transplantation. There are 60 different topics and they can all be downloaded or printed out.

There is also a section on diets for renal patients. These are all prepared by the dietitians at the Queen Elizabeth Hospital and again they can be downloaded or printed. If you don't have a computer, ask at your dialysis unit. I'm sure they would print some of them for you.

News from your Q.E.H.K.P.A.

The K.P.A. continues to be very well supported by patients, carers and friends. We have been very touched by the many letters and offers of support. Last month we were invited to a carol concert given by the Sheffield Male Voice Choir. The conductor of the Choir, Andrew and his wife to be Julie, who had a transplant last August, have nominated the K.P.A. to be the Choir's Charity for the next 12 months, which is very generous of them.

We were asked to join in the birthday celebrations of Sadie Smith who has supported the K.P.A. over many years. It was a significant birthday for Sadie. Her friends and family raised £955 for the K.P.A. Thank you Sadie.



At Christmas, the K.P.A. was able to fund festive activities at many of the dialysis units where staff or patients were

able to organise them. This is something we would like all the units to take part in, if not at Christmas time at some of the many other festive events throughout the year to suit the patients. This is made possible by the very many donations we receive throughout the year.



Research Project

The K.P.A. has agreed to support a research project which will be looking at methods to increase the time that a donor kidney can be kept before it is transplanted. Currently this is between 6 and 24 hours. If this time could be increased to a few days the benefits would be significant. There would be more time for detailed tests to check that the kidney is a match, planned surgery and hopefully more kidneys could be used. It could lead to less rejection in the short term and also reduce the amount of drugs a patient would need to take. These are a few of the benefits, The K.P.A. is supporting the funding of this research over 5 years at a cost for £20,000 per year. Again, this has been made possible by the very generous support we have had from the renal community.

Supporting Healthy eating

You should have seen the wall posters around the Units and the handouts for dietary advice. We hope you found them useful. If you want copies of these or further dietary information, they can be found on the Q.E.H.K.P.A. web site. www.kidneymatters.co.uk. These were all funded by the Q.E.H.K.P.A. from the very generous help we get from you all.

Annual Patients' Holiday

This year Sharron Pilling is organising another patients' holiday. The dates are not yet finalised, but it will be towards the end of September and will be somewhere warm and sunny. If anyone is interested, please contact Sharron Pilling. Her email is Sharon.pilling@uhb.nhs.uk phone number 07843 433808 to put your name down. Sharon will contact you with all the details as soon as they become available. This is a great opportunity for dialysis patients to have a holiday with the assurance of dialysis staff on hand to give practical support, especially if it's the first time you have ventured away after starting on treatment. Patients do have to pay for the holiday, but going away with others helps build confidence for the future.



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 in memory of loved ones to help us continue our support for patients and the Hospital.

We remember, Mr Graham Hawtin of Rushall, Mr John Sheaf, Mrs Pamela Hargest and Dr Peter Bennett.

Our thoughts are with all the families at this sad time.

New Operations Manager at W.M.A.S.

Andy Allsopp & Rob Kelly are new Managers for Non-Emergency Patient Transport within Birmingham. Both Managers have a wealth of experience within the Emergency Ambulance Service and hope their knowledge will be able to benefit the NEPT Service in Birmingham.

Andy has been in the Ambulance Service for 11 years and is a practicing Paramedic. Rob has worked in the NHS for 18 years. 16 years have been with West Midlands Ambulance Service in Emergency Operations as Controller and Control Manager.

As a Trust, they take the responsibility for transporting patients to their appointments and Dialysis seriously. "As a Trust we understand this is a demanding time for patients and the regular journeys they take for these appointments can have a massive impact on their health."

Rob has seen close friends go through this experience and understands at a personal level how this can affect an individual's life.

Because of this, they want to ensure that patients have as safe and comfortable a journey as possible. Throughout Birmingham, Renal Coordinators have been introduced to cover the units and are able to listen to patients' experiences whilst acting on queries and concerns.

Andy and Rob participate in meetings with patient representatives and operational meetings with the local Trusts to maintain an understanding of any issues arising.

Patients have access to West Midlands Ambulance Service Patient Advice & Liaison Service to raise concerns or give compliments. From this, the Trust is able to act in making changes to help patients.

With the inception of the new Pan-Birmingham contract in May 2017, some challenges have been experienced within the transition from the old to the new contract.

We have seen great improvements and acted upon listening to our patients. We have shown examples where we have taken this information, made adjustments and have received positive feedback. Whilst we know there are many challenges ahead, communication will be vital and we hope we can take them on together for the benefit of the Trust patients.

Andy Allsopp, Senior Operations Manager Arden, Worcestershire and Pan Birmingham NEPTS, W.M.A.S. Foundation Trust

If you have issues with transport, please speak with your dialysis nurse, or phone 0345 200 6867. If you wish, please contact the Q.E.H.K.P.A. and we will take up your problem appropriately.

Donations we have received

During the last few months we have been receiving many donations from patients and friends towards the work of the Q.E.H.K.P.A.. The letters with them all say how much they have appreciated the help and support they have received from all the staff at the Q.E. and the dialysis units.

Vera Masters supported us again with a Christmas market and raised £315. Mr Pemberton of King Norton donated £400. Mr and Mrs Batch sent us £200. Their son is a transplant patient and is currently cycling the length of India. We have had very many donations with raffle tickets totalling over £500. These were from Mr & Mrs McHerne, Lynne Straw, Mr Johal, Miss Willetts, Mr & Mrs Willetts, Mr & Mrs Bevan, Miss O'Tool, Mr & Mrs Blake and several anonymously.

We received a bequest of £15,600 from the estate of Mrs Grew.

Mr Kathirgamak and Mrs Morris donate with a standing order every month. Cindy Rogers again raised £102 at a dress down day at work.

We thank you all. Everyone is very generous and we are pleased to be able to help renal patients, research projects and the Hospital Renal Unit. We hope this will improve the quality of life for renal patients.

Q.E.H.K.P.A. meetings are held at the Queen Elizabeth Hospital on the 2nd Wednesday of each month at 7.30 pm 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 Q.E.H.K.P.A.

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

OR complete the section below and return to:-

Lorraine Bateman, University Hospital Birmingham NHS Foundation Trust, Room 43F, 4th 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

CONTACTS FOR THE Q.E.H.K.P.A.

Please phone, write or email if you need Information or help.

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