



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. October 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 Renal Patients treated by the Q.E. Hospital

Steve the Ironman supports the Q.E.H.K.P.A.

As a child he had no idea his dad was affected by kidney disease. Thanks to the generosity of organ donation, he'd received a transplant that meant the first 10 years of Steve's life were free from the stresses & strains of a parent on a dialysis machine 3 times a week for hours.

Being treated at the QE hospital in Birmingham, he had received support via the local Queen Elizabeth Hospital Kidney Patients' Association. In speaking with his Mum recently, he now understands his Dad was one of the founding members.

Local charities such as these might not get mainstream attention, but for "patients on the ground", can be invaluable in terms of day-to-day support & guidance. When you are constrained by the dialysis machine, having an organisation that can provide you with helpful information, and arranging dialysis partnerships at other sites for holidays, can offer a brief sense of freedom. Families of patients are supported too.

The event he undertook was the "Ironman Copenhagen", 3.8km swim, 180km bike ride & a 42.2km run. He has done half marathons, marathons, triathlons, half Ironman triathlons, and generally taken them in his stride. In reality, he would have felt guilty about asking for donations for a "challenge" that he knew was well within his capabilities.

The sponsored event raised £2000 for the Q.E.H.K.P.A. On Transplant Day, Steve presented us with a cheque for £2000. Our thanks to Steve and all who supported him.



£2000 donated by Steve

National Transplant Week, 3rd September

The Q.E.H.K.P.A. together with the Kidney Transplant Team organised a stand in the Atrium of the Hospital to raise awareness of the importance of Organ Donation and to encourage people to sign up to the register.

We also informed people of the importance of letting their family know of their wishes as it is their decision to go ahead with organ donation irrespective of your wishes.

The day went very well with lots of interest shown. Very many were interested to find out more about transplantation and in particular the Paired Exchange Scheme. This is when a patient who needs a transplant and a friend or relative is willing to donate, but unable to due to being incompatible, the Scheme looks and hopefully finds a donor and recipient. By doing a switch, both parties donate and both recipients receive a kidney. This process can take some time but it works and many patients have benefited. If you wish to find out more about this please speak to the Transplant Coordinators when you have a clinic visit.



Important information for Transplant Patients.

Your Immunosuppressant is changing

Over the coming 12 months the Q.E. Kidney Transplant Service is changing its brand of Tacrolimus immunosuppression from **Prograf®** to **Adoport®**.

Tacrolimus is an immunosuppressive drug that is used to help stop your body from rejecting your kidney transplant.

The brand change is being driven by N.H.S England to ensure the best possible use of NHS resources. This change will ensure that all patients continue to receive the best possible care whilst delivering services in the most cost-effective way.

Remember:- Prograf® and Adoport® are different brands of Tacrolimus which is used to help stop your body rejecting your kidney transplant.



Do not stop taking your medication. If you have any questions please contact the Renal Department at the Hospital.

This information is provided by the U.H.B. Transplant Service.

Update on a research project that we have supported

This is a 4-year research project to increase the time a deceased donor's kidney can be kept before transplantation

Using the generous research support grant from the Q.E.H.K.P.A. the renal transplant surgery research group has carried out a series of laboratory studies looking at the role of kidney storage fluid oxygenation in the hours prior to the transplant operation itself.

We are delighted to report that this work has been accepted for publication in the reputed journal Transplantation. Using a novel methodological approach developed in Birmingham (¹³C 2D NMR/GCMS), we have clearly demonstrated that oxygenation alters the active metabolic pathways in this highly non-physiological environment. Indeed, a downstream consequence of this was the

demonstration of greater levels of ATP, the cellular energy currency, in the oxygenated kidneys.

This work has furthered our understanding of how best to preserve deceased donor kidneys in the pre-transplant period and we believe that optimising the kidney during this storage period will ultimately result in improved outcomes for transplant patients.

Further studies are now underway to determine the optimal concentration and duration of oxygenation during this critical time period.

Mr Jay Nath FRCS PhD. Surgical Registrar. Department of Renal Transplantation, Queen Elizabeth Hospital

The success of this project would be of tremendous benefit to all those waiting for a transplant as it would increase the number of kidneys available.

Continued support from Patients and Friends

In the last edition of Kidney Matters we reported how well Stacey had done in raising funds for the Q.E.H.K.P.A. and we were very pleased that her employer Standard Life added a further £1625 in their "Raise and Match" scheme. Thanks again to Stacey and Standard Life.

Also in June Kidney Matters, Helen raised £535. Her niece organised a Dress Down Day and her employer, Suzuki GB. PLC, donated £209. There was also another donation of £100. Thanks to everyone for their support.

We are also grateful for all the support the K.P.A. has received from patients, families and friends with donations or fundraising.

These include Jerry Duggan, Mrs Ann White, Mr and Mrs Burns, Miss J. Johnson, Philip King, Jane Weir, Brownhill Tangent Club, Pauline Crook and Vince Essex.

All these enable us to support the projects that will help the future of renal treatments.

Visit our website www.kidneymatters.co.uk

- For more information about what we do.
- Patient information.
- How people are supporting the K.P.A.




Patient Information

On our website, we have started a new section under Patient Information, Peritoneal Dialysis. It will include hints and tips about being on and using P.D. We invite anyone who has any ideas or suggestions which would be useful to pass on to other users to help make P.D. easier and better. All the ideas will be checked by the Hospital to ensure information is safe and accurate to distribute to patients.

If you go on to the Q.E.H.K.P.A. Website 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. There is also a section on diets for renal patients 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, or contact the Q.E.H.K.P.A and we will send them to you.

Q.E.H.K.P.A. Annual Raffle BIG PRIZES TO BE WON



Queen Elizabeth Hospital
Kidney Patients' Association
Q.E.H.K.P.A. Annual Raffle 2019
FIRST PRIZE £500
SECOND PRIZE £250
THIRD PRIZE £125
5 PRIZES of £50 & 5 PRIZES of £25
TO BE DRAWN ON 9TH JANUARY 2019

TICKETS
£1
EACH

We are again organising our annual raffle. Please support us by buying a book. We have enclosed one book of 5 tickets which is sent to every renal patient treated by the Q.E. All the money we raise is used to support the Renal Unit, Dialysis units and renal research projects. If you require more books please contact one of the Committee, details on the back page. When sending in cheques please make them payable to Q.E.H.K.P.A.

We have increased the prize fund with a first prize of £500 so please have a go and support your charity.

Project to help female renal patients through pregnancy

The Queen Elizabeth Hospital renal department runs one of the largest joint renal-antenatal clinic services in the UK, in conjunction with Birmingham Women's Hospital. Although many women with chronic kidney disease have successful pregnancy outcomes, they have a higher risk of potentially serious pregnancy complications such as pre-eclampsia. The exact causes for pre-eclampsia are poorly understood and currently the only definitive curative treatment is delivery of the baby and placenta. When pre-eclampsia occurs early in pregnancy, premature delivery is often necessary, leading to potential health problems for mother and baby.

There is increasingly strong evidence that 'complement' proteins may play a crucial role in the development of pre-eclampsia. These proteins normally circulate in blood and tissue fluids and can become

activated as a response to inflammation. We have recently commenced a research project in conjunction with Birmingham Women's Hospital, examining levels of complement proteins in differing tissues (maternal blood, placenta, urine and umbilical cord blood) in women with pre-eclampsia, compared to healthy pregnant women. We hope this work will strengthen the evidence base behind the role of complement in pre-eclampsia, and potentially lead to the development of complement inhibiting treatments that could slow down the development of pre-eclampsia and improve pregnancy outcomes for affected patients in the future. We are grateful for the support of the Q.E.H.K.P.A., without which carrying out this important research would not be possible

Hannah Blakey (Doctor) JSD Higher - Renal Medicine

Dialysis Units

Just a reminder to all the Dialysis Units. Over the past year and longer for some units, we have been given money to be used by the units to support patients. This could be used to have a festive party or

towards an outing or a social get together with a few snacks at lunch time. If you have any ideas talk to your Unit Manager and contact the Q.E.H.K.P.A. and let's see what we can do.

We would like to obtain your views on how Patient Transport is working for you.

We are just over 12 months into a new patient transport contract (NEPT)

We want your views on how the service is meeting your needs.

Please answer the following question and send them back to the Q.E.H.K.P.A. There is **no need** to put your name or address, just where you use transport ie name of dialysis unit, clinic or Hospital.

1. Do you get a message that the transport is on way YES NO
2. Are you being picked up at the time you expect YES NO
3. Do you arrive within 45 minutes of your appointment time YES NO
4. Are you collected within 30 minutes of being ready after treatment YES NO
5. If NO, how long after 30 minutes do you wait: 15min 30mins 45min 1 hour – longer, state time.....
6. Do you arrive home within a reasonable time, allowing for time of day and traffic YES NO
7. Are you satisfied with the service you are getting Yes NO

Please return to me Nick Flint Chairman Q.E.H.K.P.A. My address is below

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Climbing and Running to support the K.P.A.

We were very pleased that two more supporters of the K.P.A. have started fundraising pages on MyDonate.

Chris Millington is running the Birmingham Half Marathon and is raising money for us and New Cross Hospital as both his parents have been treated by these Hospitals.

Stephan Betteridge is Trekking the Annapurna Circuit in the Himalayas next January. He is doing this in memory of his Mother-in-Law who was a renal patient at the Q.E.

There are more details of their events on the web site www.kidneymatters.co.uk

MyDonate is an excellent way to support us as there are no costs or charges to us therefore all the money raised comes to the 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 in memory of loved ones to help us continue our support for patients and the Hospital.

We remember: - Mrs Ruth Richards, Mr Paul Parslow, Mr Robert Coley, Mr Morris, Mr Trevor Evans, Mr Michael Thornton, Ms Enid Davis, Brian West and Mr Arthur (Jim) Richardson.

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

Queen Elizabeth Hospital Kidney Patients' Association meetings

The Q.E.H.K.P.A. meet every month except August and December at 7.30 pm in the Faith Centre at the Queen Elizabeth Hospital on the 2nd Wednesday. Everyone is welcome to come along.

Please phone 07720597468 to check that we have not changed the date due to unforeseen circumstances.

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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