



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. October 2017
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 HDD, 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

Q.E.H.K.P.A. Receives Donation of £100,000.

The Q.E.H.K.P.A. Has been very generously gifted £100,000 by Mr Ayres who sadly passed away recently. His wife was a dialysis patient and had a transplant. She was treated by the Q.E. for many years before she passed away. They both supported the Q.E.H.K.P.A. and the Hospital.

We are very grateful for this donation which is to support the renal patients and the renal units at the Queen Elizabeth Hospital. We will be having discussions with the Consultants and Management of the Hospital to ensure the money is put to the best possible use to benefit all Renal patients treated by the Q.E. and at the dialysis units around the area.

This donation will enable us to give even more support to the projects that we undertake.

Our sympathies go to his family and friends at this sad time.

Q.E.H.K.P.A Provide TV for C.A.P.D. Patients' Waiting Area.

The Q.E.H.K.P.A. has funded a television in the patients' waiting area of C.A.P.D. This will help patients to pass the time when at the unit while they are having treatments. Patients at C.A.P.D. often have to be at the unit for long periods of time waiting while tests and treatments are undertaken. So to try and make it more comfortable it was decided a television would help.

The cost of the television plus installation of the aerial and fixings was £1600. Thanks to the many donations we receive we are able to fund these projects to help support patients.

Last year we provided new chairs for this area. This now completes a new look for C.A.P.D. patients' waiting area.



We now have the left wrist bands with **white** lettering

FISTULA LEFT ARM+ NO NEEDLES OR BP TESTING+ Q.E.H.K.P.A.

We have now a stock of left wrist bands for dialysis patients.

They are available in 3 sizes, large, medium, and small. They are free for patients treated by the Q.E. or at any of the dialysis units. We have sent a small selection of each size to each unit so please ask the staff for one. There are some available in the Renal Outpatients unit, so ask the phlebotomist for one. If you want to send for one please enclose a stamped addressed envelope with a 76p stamp to cover postage, to Nick Flint address on back page.

We still have a quantity of right wrist bands but they do not have the white lettering.

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

We have enclosed a £5. book of raffle ticket. This is the only time we ask patients and friends to support the Q.E.H.K.P.A.. There are cash prizes to be won, a first prize of £300. You may have received raffle ticket to support other renal charities but this is the only one which is to support the Renal Patients treated by the Queen Elizabeth Hospital.

We take this opportunity to thank all those who support us with fundraising for without your generous help we would not be able to continue our work. If you would like to have extra tickets please contact us.

Five Ways Health Centre in Ladywood, Supports Q.E.H.K.P.A.

Five Ways Medical Centre in Ladywood decided to organise a fun run to support the Queen Elizabeth Hospital Kidney Patients' Association.

The event was in memory of Mr Sant Surjit Singh Surdhar who was a renal patient at the Queen Elizabeth Hospital.

The event was held on the 1st July and about 150 friends relatives and patients at the practice joined in with the run. The staff at the centre organised refreshments for all who took part.

The event raised £8500 for the Q.E.H.K.P.A. The money will be used to support renal patients and the Hospital.

The K.P.A. thank all the staff and those who took part on the day and for their very generous support.

Gush Surdhar Practice Manager, Gemma Mooney. Admin manager organised the event, and members of the staff at the health centre are in the picture.



Organ donation week 2017

The week started with a thanksgiving service held at St Stephens Church, Redditch. The service was organised by Lady Whitfield. Her father was the oldest patient to receive a heart transplant and was the oldest living recipient when he passed away aged 92. The service was a very emotional occasion with donor families and recipients expressing what it meant for them. There was a talk by Mr Majid Mukadam MBE who is the Retrieval Heart Lung Transplant Surgeon at the Q.E.. He spoke about his work and how he and his team dealt with a very sensitive and emotional time for families.

We were treated to singing from the Arrow Vale Singers and Gemma Turner.

The High Sheriff of Worcester Mr Stephen Betts together with the Deputy Mayor of Redditch, Local Councillors and the MP for Redditch all attended.



The Q.E.H.K.P.A. continued its support for Organ Donor Week in the atrium of the Q.E. on Monday 4th September with the Q.E. Transplant Coordination Team. We were promoting organ donation and discussion with patients and public about what is involved with organ transplantation and the benefits for those involved. Very many people asked for information and there was the opportunity for those who were waiting for a transplant or who had recently had one to meet and talk with others who had been through the system with several years of experience of life after transplantation.



If anyone wants further information on this subject please feel free to contact the Q.E.H.K.P.A. or the Transplant Coordination Team at the Q.E.

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, Melinda Kaur, Alan Wilcox, Thomas Berry, Duncan Edwards, Ecclestone Hamilton and Mrs Margaret Grew.

Our thoughts are with the families at this sad time.

Donations we have received

We would like to thank all those who have supported the Q.E.H.K.P.A. recently with donations. These include:- Jeremy Duggar who raised £115, also the three patients who make a monthly donation to us. We would like to thank the patients, friends, and relatives who have supported the fundraising events that we have reported on in this edition of Kidney Matters.

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.....

No longer a patient at Q.E.

Address.....

Please do not send

Post Code.....

General information about Kidney transplants

The purpose of kidney transplantation is to give a healthy kidney to a person who has kidney disease. A successful kidney transplant may prevent the need for dialysis and the complications associated with kidney failure. For many years, the kidney that was transplanted had to come from a person who had died, from a

Here are some answers. We hope this helps you to understand more about a Kidney Transplant.

Myth -1: A kidney donor will have to take medications for the rest of their life

Fact. A kidney donor will be given prescriptions for pain medication and stool softeners at discharge from the hospital. These are only for the immediate post-operative period, after that time, a donor does not have to take medication as a result of being a donor.

Myth -2: A kidney donor will have debilitating pain for an extended period of time.

Fact. A kidney donor will have some pain after surgery from both the incisions and related to gas and bloating. This pain will diminish in the days following surgery and can be controlled with pain medication if necessary.

Myth -3: A kidney donor will be on bed rest following surgery.

Fact. A kidney donor will be out of bed and walking independently before discharge from the hospital.

Myth -4: A kidney donor will be in the hospital for an extended period of time after surgery.

Fact. A kidney donor will be hospitalized for two nights (i.e. if surgery is on a Tuesday, the donor will typically be discharged on Thursday).

Myth -5: A kidney donor can no longer participate in sports or exercise.

Fact. A kidney donor should be able to return to regular activities and exercise at approximately 4-6 weeks following surgery.

Myth -6: A kidney donor will have to follow a new diet plan following donation.

Fact. A kidney donor should eat a healthy, well balanced diet. There are no dietary restrictions following donation.

Myth -7: A kidney donor can no longer consume alcohol following donation.

Fact. While excessive alcohol use is always dangerous, a kidney donor can consume alcohol in moderation.

Myth -8: A female kidney donor should not get pregnant after donation.

Fact. A female kidney donor should wait 3-6 months' time after donation to become pregnant. The body requires

"deceased donor." But there are not enough deceased donors for the number of people who need kidney transplants. Although living donor kidney transplantation is becoming more common, there are still many myths associated with living donor kidney transplantation.

time to recover from the surgery and to adjust to living with one kidney prior to pregnancy.

Myth -9: A kidney donor's sex life will be negatively affected by donation.

Fact. A kidney donor may engage in sexual activity when they feel well enough to do so.

Myth -10: I'm too old to be a donor, you wouldn't want my organs?

Fact. Age is not always a barrier. All people who would like to be considered as donors will have to undergo a detailed medical assessment to ensure they are fit and well enough to donate. This assessment can take 18 weeks plus depending on the patient.

Myth -11 It's against my religion to be a donor?

Fact. All of the UK's major faiths including Buddhism, Roman Catholicism, Christianity, Hinduism, Judaism, Islam and Sikhism support organ donation and transplantation.

Myth -12 Can I donate to my recipient if our blood groups do not match?

Fact. Yes you can if this is possible. The living donor team would discuss this in detail with you and also discuss other transplant options/schemes available to them.

Myth -13 If I donate will I experience financial difficulties, as I will not be able to work?

Fact. No, there is a fund available for donors who have donated and any financial losses are reimbursed. The living donor team will discuss this with you.

Myth -14 Can I donate my kidney to anyone?

Fact. Yes we have an increased number of donors who have come forward to donate their kidney to benefit someone in need. These incredible 'altruistic donors' have really had an impact on people lives who are waiting for a kidney transplant. A lot of these donors participate in the National Living Donor Kidney Sharing Scheme, where because of their generosity the- 'gift of life' can assist in promoting more than one kidney transplant.

Living Kidney Donors

Living donation is a way for people to receive an organ and/or tissue for transplants. Before you can become a living donor, The Hospital will carefully assess you to make sure:-

- It is safe for you to donate.
- The organ is suitable for the person receiving it.

Kidneys are the most common organ donated by a living person. About a third of all kidney transplants carried out in the UK are from living donors. A healthy person can lead a normal life with one working kidney.

Who patients should contact and talk to.

If you would like further information, please contact the Live Kidney Donor Team on 0121 371 5845 and ask to speak to a Living Donor Coordinator. The Q.E also has a group of patients who are "Peer Supporters" who have experience in living transplantation and are able to meet and talk about the issues involved.

There is also information on our web site www.kidneymatters.co.uk which we hope will answer some of your questions. You can also ask your Consultant when you have your next clinic appointment.

Recently a couple both in their early 80's, the husband donated a kidney to his wife. Both are doing very well. Think about it and don't hesitate to ask.

Open day at Smethwick Unit for new patients

The day was organised by the Q.E. Renal Community Team for patients who are approaching the need for dialysis and to show them the options and the opportunity to talk to patients who have experience of the different treatments available to them. New patients had an opportunity to see a dialysis unit and to talk to patients. They were also shown the different options for treatments: Unit based dialysis, home dialysis and C.A.P.D. and its different options.

A home dialysis patient demonstrated home treatment. The visitors could meet patients who were using different types of dialysis and had been dealing with life and being a renal patient on dialysis.

The prospect of having to have dialysis is very daunting and to talk to someone who has experienced it is very helpful and finding out how it would fit into their life and work is very important. If anyone wishes to talk or meet someone to discuss issues, there is a very good Peer Support team at the Q.E. with patients who are able and willing to help new patients. If you would like more information just ask one of the staff at clinic to put you in contact with the Peer Support Team.

A patient's story: By John and Yvonne

On Saturday 1st July we were invited by the Home HD Team at Smethwick to take part in their first open day for people who are thinking about home dialysis. John (in the picture, the patient) and I (the carer) have been undertaking home haemodialysis since last September and for us this has proved to be really successful and is certainly worth a consideration for many patients who could be suitable. The thing about home dialysis is that you can fit it around your lifestyle.

It is always good to have a choice in the treatment you undertake and obviously with the advice of the Consultants and Specialist Nurses at the Q.E. we went down the route of haemodialysis. There are other options available and this was what Saturday 1st August was all about.

There were different types of dialysis equipment on show with a number of patients, carers and specialist people to offer advice and answer any questions.

We undertook John's dialysis on that day so that people could see what was involved from both a patient and a carer's point of view. It is often the simplest of

things that cause the most worry and to be able to demonstrate how it works and clear up some of these worries and niggles has hopefully helped people overcome some of fears of what home dialysis involves.

Our initial training lasted for six weeks and was extremely thorough thanks to the very patient and dedicated team at Smethwick. It is a big decision to make which may not suit everyone and there are many things to be considered as we all have different requirements, but it has meant that John has been able to continue working and enjoys arranging his life around dialysis to suit himself rather than at predetermined times.

As long as you follow your training and instructions it is not as daunting as you may think and I hope we have enabled patients to come to a decision following the successful first open day at Smethwick.



We threw a party for Matt to help the K.P.A



We threw a surprise celebration party for Matt's transplant & thought we would ask everyone attending for a donation of £2 each. We also asked local businesses in Willenhall to donate prizes for a raffle. We had over 60 prizes donated, from flower bouquets, restaurant vouchers, health and beauty vouchers & concert tickets. We sold raffle tickets in our work places, town centres etc to raise the money. We raised £933.

Matt is now 6 months post-transplant and is doing really well, he was first diagnosed with chronic kidney disease when he was 13, and had to go on haemodialysis when he was 25 years old. He was on it 2 and a half years before he got the call for his transplant, from a deceased donor. We have two children ages 6 and 1, and are looking forward to enjoying life again, going on holidays abroad & dining out.

We would like to thank all staff at the Queen Elizabeth Hospital for their kindness, and all their help. They do a brilliant job.

Laura and Matt

Thank you and very well done, and for coming along and helping post all our newsletters

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 K.P.A.

Chairman/Kidney Matters Editor Nick Flint 9 Brookhouse Road Walsall WS5 3AE Tel:- 07720597468 Email nick.flint@live.com	Secretary Joan Ingram 6 Cremorne Road Sutton Coldfield West Mids B75 5AW Tel:- 0121 308 0024	Treasurer Len Ingram 6 Cremorne Road Sutton Coldfield West Mids B75 5AW Tel:- 0121 308 0024	Vice Chairman Dawn Roach 181 Wolverhampton Road Pelsall Walsall WS3 4AW Tel:- 07533097655
---	--	---	---