



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. June 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

World Kidney Day 8 March 2018

The day went very well. The Q.E.H.K.P.A. were very well supported by the staff of the Renal Department of the Hospital.



We had lots of interest from members of the public enquiring about renal treatments, how to stay healthy and dealing with a renal condition. Having staff on hand to answer questions on diets, transplantation and different types of dialysis helps very

many people.

This year is the 50th anniversary of the first Kidney Transplant at the Q.E. and was of particular interest to many people. We were very pleased that Peter Ford was able to join us as he has had his kidney for 42 years. This is very encouraging to all those who have had a transplant and to those who are waiting for one. It shows that a kidney transplant really is life changing and can be very very successful.



Q.E.H.K.P.A. donates £100,000 for Transplant Research

On World Kidney Day the Q.E.H.K.P.A. were very pleased to be able to hand over a cheque for £100,000 to Mr Andrew Ready, Consultant Transplant Surgeon.



The money will be used over the next 5 years to assist in the research to enable a donor kidney to be kept for a longer period of time before being transplanted to a recipient. Currently it is about 6 to 24 hours. This gives very little time to make sure the matches are the best they can be and the recipient has little notice of surgery. Being able to extend the time the kidney can be kept would be very beneficial to all involved. Hopefully it will mean higher success rates, better outcomes, planned operations and opportunities to improve the match of the kidney. This we think will increase the number of kidney transplants and improve lives for patients.

The Q.E.H.K.P.A. thank all those who over the years have so very generously supported us to enable this and other important research projects to continue.

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.

Update on projects the Q.E.H.K.P.A. have funded and supports

The Q.E. Renal Unit are working on a number of exciting projects with researchers at the University of Birmingham focusing on the ground-breaking use of a new innovation known as 'ePROMs' (electronic patient-reported outcome measures). This is the first in a series of articles highlighting these important projects and their findings.

So, what are ePROMs? They are simple online questionnaires that patients can complete at home using a PC, tablet, computer or smartphone, so that the kidney care team can monitor their condition in real-time. This information could help both patients and their clinicians to manage their care better.



The use of ePROMs has been shown to improve the care of cancer patients in the US by reducing A&E visits and hospitalisations and improving quality of life and survival. The hope is that they may also be helpful for patients with renal disease and this is something that the Q.E. Renal Unit and the University of Birmingham are keen to test.

As part of this process, the RePROM Trial, a 4-year research study, is about to start piloting an ePROM system for Q.E. patients with advanced CKD. For further information about the study please see the website www.birmingham.ac.uk/RePROM or follow the team on Twitter @re_prom.

We will keep you posted on this and other ePROM projects in future newsletters

Another project we supported

Despite the majority of renal patients requiring vascular access for dialysis it is an area that has not received as high a profile as many other areas of kidney treatments. The renal team at Q.E.H. are leading the way with new research in the area. This was stimulated by a Q.E.H.K.P.A. funded project which looked at the use of a drug (GTN) on a patch applied at the time of surgery.

This randomised controlled trial, published in the prestigious British Journal of Surgery, aimed to promote fistula outcomes. The overall results from this study were very good but failed to show a significant benefit for the drug. This importantly demonstrated that Q.E.H. is able

to deliver such studies and has the invaluable co-operation of Q.E.H. renal patients in world class research. This study has led to the Q.E. being chosen to lead on a number of high profile studies relating to dialysis access (*endoAVF/Hamacyte artificial graft/drug eluting balloon/Vascular access questionnaire study*) and demonstrate how the funding of projects by the Q.E.H.K.P.A. go on to allow local patients to benefit from new technologies and advances that would be otherwise unavailable.

Mr. Nicholas Inston Renal Surgery - Consultant

Funding research into pregnancy for renal patients

We have committed to fund a £15,000 project to assist female renal patients in pregnancy. This is being led by Mr Graham Lipkin. He has been doing very important work in this area which has had great outcomes for many ladies. At World Kidney Day we had lots of happy family photos of mothers and their young children who had been helped by this important piece of work.

P.D. Department to receive our support

The Q.E.H.K.P.A. have been asked to fund a project to produce patient information for dialysis patients who are choosing to use peritoneal dialysis, either daytime or overnight treatment.

This will be in the form of a video and available to patients in different formats. It will cover all aspects of the treatment, helping patients to make the right choice for them. The information will show patients how the process works and advice on using the system and living with it.

We think this will be of great benefit to patients using peritoneal dialysis.

The cost of funding this is £10,000 and the Q.E.H.K.P.A. has agreed to fund this project.

Thanks from the Q.E.H.K.P.A.

The Q.E.H.K.P.A. is very pleased to be able to support such a wide variety of research projects to help renal patients on PD, Haemodialysis and Transplants. Research is an important way forward to improve our lives as renal patients.

Thanks to the very generous help and support the Q.E.H.K.P.A. receives we are able to continue to fund these projects. We thank you all for your many donations

and fundraising efforts for without them these projects would not happen. We thank Tony Hale who continues to do after dinner speaking and donated £75, J Peters £690, Mrs A. White donated £100, The Templeton Lions Club £100, and Mr and Mrs Guy who celebrated their 60th Wedding Anniversary and donated £300. *Thanks to all.*

Stacey donated a kidney to help her Mum and also supported the Q.E.H.K.P.A.

I found out the incredible, life changing news in October 2017, that I was in the amazing privileged position to donate one of my kidneys to my Mom.

My brother and I are not a direct match, so we have been on a paired exchange list for the last 4 years. This is where a relative, friend or partner is fit and able to donate a kidney, but is incompatible with the potential recipient and they are matched with another donor and recipient in a similar situation, so that both people in need of a transplant receive a compatible organ.

I'm extremely pleased and over the moon to tell you that our surgeries went ahead in January and everyone involved is recovering well. There are no words to describe how mind-blowing and astounding this is.

I'm making it my mission to raise awareness of living organ donation and the paired exchange scheme that is available in the U.K. and The Republic of Ireland.



I'm originally from Redditch, UK and have been living in Dublin for the last 7 years. Our operations took place at The Q.E. Hospital, Birmingham. The team in Ireland have been out of this world and we can't thank them enough. Beaumont Hospital have also been very supportive and have taken bloods for me on occasion, to save me travelling.

We want to raise as much as possible for the Q.E.H.K.P.A. and the Irish Kidney Association. Both have supported us and many other families across the U.K. and R.O.I. and we want to give something back. So we've hosted a Big Kidney Quiz in the UK and in the Republic of Ireland. In Ireland we raised €2966 for the Irish Kidney Association. The Quiz in Birmingham took place in April and we were very pleased to have raised £1625.09 for the Q.E.H.K.P.A.. It is hoped my employer Standard Life will "Raise and Match" this with an additional £1625 to help them to continue their work in supporting Renal patients and the Queen Elizabeth Hospital Renal Department.

By Stacey

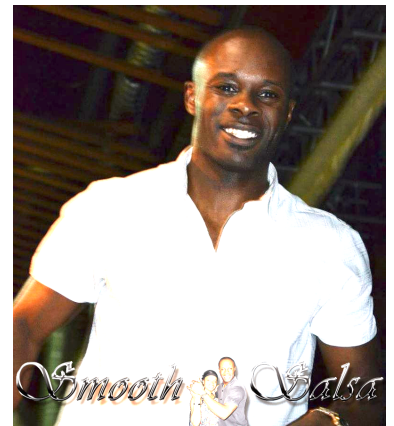
£3500 raised in Memory of Stefan

I am a local Birmingham based Salsa Teacher and I have been teaching Salsa for over 20 years. My trade name is Smooth Salsa and I met Stefan through the local dance scene many years ago, he also attended my classes and events.

When we learned of Stefan's passing a few of us decided that we wanted to help the family with funeral costs but fortunately, the family already raised the funds for that before the funeral. So I decided the next best thing would be to help others with Chronic Kidney Failure and so I organised the event to try and raise as much money as possible for Kidney Research at the Queen Elizabeth Hospital.

I organised the event and rallied the support of the local Salsa and Kizomba Dance scene to come together, which they did and we had a great night, for an extremely good cause. My only regret is that this is the first charity event I have ever done, but it will definitely not be the last!

Kind regards, Michael Pottinger. *Thanks Michael for your support.*



Around the dialysis units.

At the Q.E. there are 11 dialysis units plus patients who dialyse at home and we would like to support them more. We have many donations from people or groups who ask that the money be ring-fenced for a particular unit. This could be used for outings or buffets on special occasions. We would like ideas and help with this so that the Q.E.H.K.P.A. can support as wide range of patients as possible. Please let us know by contacting the Q.E.H.K.P.A. or ask the Unit Manager to contact us with your ideas.

If you are having a party or an event please let us know and we can post details on our website or in

Kidney Matters and inform others about what is going on. This could give ideas to others to organise for their own unit.

We keep talking about transport but if you are having issues it would be very helpful if you could let us know about them. The K.P.A. have regular meetings with the Commissioners and W.M.A.S. and to have details of experiences good or not so good would be very helpful.

Contact details for the K.P.A. are on the back page.

Handsworth Lions Club fundraiser for the K.P.A.

On Saturday 19 May the Birmingham Handsworth Lions Club held a Bollywood and Ghazal Night with Qammer Ali Khan & Kumari. The night was very well supported with about 200 people attending, it was a very entertaining and enjoyable evening with song and dance and a meal in the interval. The event raised £2000 for the Q.E.H.K.P.A. and also raised awareness of organ donation and transplantation.

Our thanks to the Birmingham, Handsworth Lions Club President Vikram and Chandrakant Patel for their generosity in supporting the Q.E.H.K.P.A.



Helen celebrates her 60th birthday and 1 year with a transplant

I will be celebrating my 60th birthday in April this year, and the first anniversary of my kidney transplant in May. I want to thank the Queen Elizabeth Hospital and more importantly my amazing brother Aidan for a successful kidney transplant.

The transplant has transformed my quality of life enormously. I was extremely lucky to receive the transplant before I had to go on to dialysis. Others are not so lucky and require the support of this charity which also raises funds to research methods of increasing the time that kidneys can be kept before being transplanted. This is currently only 6 - 24 hours. Lengthening this time would allow more transplants to take place, enable better matches, less rejection and also reduce the amount of medication required by post transplant patients.

Well done and thank you. Helen raised over £500 for the Q.E.H.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 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.

NOTICE

Queen Elizabeth Hospital Kidney Patients' Association ANNUAL GENERAL MEETING

Notice is hereby given that the Annual General Meeting of the
Queen Elizabeth Hospital Kidney Patients' Association
will be held in the Faith Centre of the Queen Elizabeth Hospital Birmingham
on Wednesday 11th JULY 2018 at 7.30 p.m.

AGENDA

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| 1. Apologies for absence | 5. Treasurer's report |
| 2. Minutes of the last A.G.M. held on 12th July 2017 | 6. Election of Officers and Committee |
| 3. Matters arising | 7. Appointment of Auditors |
| 4. Chairman's report | 8. Any other business |

*Nominations for Officers or Committee Members should be proposed and seconded and sent to our Secretary before the start of the A.G.M.
For and behalf of the Association. Joan Ingram, Hon Secretary.*

Contacts for the Q.E.H.K.P.A.

**Please phone, write or
email if you need
information or help.**

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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.

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

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.....

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No longer a patient at Q.E.

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Please do not send