



KIDNEY MATTERS

The Newsletter of the
Queen Elizabeth Hospital Kidney Patients' Association
JUNE 2019

VISIT www.kidneymatters.co.uk

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 2600 Renal Patients treated by the Q.E. Hospital

World Kidney Day 2019

The K.P.A. together with the members of the Renal team at the Hospital celebrating World Kidney Day. All promoted their work in supporting Renal patients treated by the Hospital. The stands included Dietitians with advice on eating well and keeping healthy. The Diabetic Nurses were on hand to talk about the importance of a healthy life style and regularly having eye screening tests as renal patients are at risk of diabetes and diabetes can lead to renal issues.

The Dialysis Nurses were showing the different types of dialysis available to patients and able to give advice and ideas about going on holiday with dialysis.

The Queen Elizabeth Hospital Kidney Patients' Association were also very pleased that Steve Betteridge was able to join us on the day. He had organised a sponsored walk trekking Annapurna in the Himalayas earlier this year and raised over £4000 for the Q.E.H.K.P.A. This was a very generous amount and our thanks go to Steve and all his friends, relatives and work colleagues who supported him. **Well done and thanks.**



A way to support the Q.E.H.K.P.A. for free

THE K.P.A. has signed up with Amazon for their "Smile Amazon". What we would like you to do, if you use Amazon, register with "SMILE AMAZON". It comes up on the first screen. You then can register and choose a charity to support. We hope you will select the Q.E.H.K.P.A.. That's all. Every time you go to Amazon go to Smile Amazon and then carry on as normal. The benefit is that every time you buy something the Q.E.H.K.P.A. gets 0.05%. It doesn't sound a lot but if everyone joins in, it will mount up and it does not cost you or us anything.

We do not receive any information as to who is signed up or how much is spent.

Please give it a try and help the Q.E.H.K.P.A. Thanks.

Kidney Matters

This is the name of our Newsletter to all renal patients treated by the Q.E and also the name of our website. This has been used by us since the Queen Elizabeth Hospital Kidney Patients' Association was formed 38 years ago. Regrettably another organisation has started to use our name for its magazine which you may come across. This magazine is nothing to do with the Queen Elizabeth Hospital Kidney Patients' Association or the Hospital.

Thanks to an important supporter of the K.P.A.

The Queen Elizabeth Hospital Kidney Patients' Association wishes to thank Tony who assists us with our web page. He does a great job and without him we would not have the web site. He sets it up and assists when needed so we can put information on quickly and easily for the benefit of patients.

Summer foods and barbecues on a renal diet

We all love a delicious barbecue when summer is here and being a kidney patient should certainly not stop you from enjoying this. When the sun is out you too can enjoy a BBQ with your friends and family. The following are some suggestions on how to enjoy the food but still look after your kidneys:

Meat and fish – you can enjoy the usual burgers, and sausages but chicken and fish are great choices too. You can make your own chicken or fish kebabs or buy some of the ready made ones in the shops. Get creative and make your own marinades or salt free seasoning mixes to add extra flavour.

Vegetarian – grilled halloumi or halloumi kebabs made with peppers, courgettes and onion are delicious. You can also get vegetarian or vegan ‘sausages’ and ‘burgers’

Vegetables and salad – if you are following a low potassium diet then a mixed salad with lettuce, cucumber, spring onion and white cabbage is fine.

If you want to make homemade kebabs a couple of pieces of pepper, courgette slices and onion can be added. Avoid mushrooms and tomatoes if you need to limit your potassium intake. Rather than have potato salad you can have some pasta or rice salad.

Sauces, dressings and condiments –

These can sometimes be very high in salt so only have small amounts. If you are hosting a barbecue, then you could also make your own barbecue marinade or other dressings such as a fresh herb vinaigrette.

The following no added salt seasoning mix recipe is great to use as a marinade for chicken and meat, Just add a small amount of olive oil with some of the seasoning mix and leave to marinade in the fridge before cooking. You can make a batch and use it throughout the summer:

Mix together:

2 tablespoons onion powder

2 tablespoons garlic powder (not garlic salt)

2 tablespoons smoked paprika

2 tablespoons mustard powder

2 teaspoons dried thyme

1 teaspoon pepper

Any unused mix can be stored in an airtight container for up to one month.

If you know you are going to a barbecue, plan your fluid intake to save extra for when you are enjoying the barbecue. Top up your glass with frozen lime or lemon wedges and sip slowly from a small glass.

As barbecue foods tend to be a rich source of phosphate try and remember to take your phosphate binders if prescribed.

If you want more information on food and drinks to enjoy at a barbecue speak to your renal dietitian.

Let's hope the sun shines a lot this summer!

Information provided by the Renal Dietitians, Queen Elizabeth Hospital

An update on some of the exciting ‘ePROM’ research being conducted by The University of Birmingham, supported by the Q.E.K.H.P.A.

We were introduced in a previous newsletter but a reminder that ePROMs (electronic Patient-Reported Outcome Measures) 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 means that action can be taken straight away if there is a problem, rather than waiting until the next clinic appointment. The system can therefore help improve communication between patients and their clinicians, leading to better care and outcomes. The system has been developed in partnership with patients and is currently being tested in the RePROM Trial. This is a 4-year research study involving patients with advanced chronic kidney disease (pre-dialysis) based at the Q.E. This project would not have been possible without the full involvement and enthusiastic feedback of patients who shared their ideas during the open session which took place in the early phases.

RePROM is recruiting during the Tuesday afternoon Q.E. clinic. Thirty patients have signed up so far. RePROM is aiming to recruit a total of 66 by October 2019. If you attend that clinic and are interested in getting involved, please speak to one of the research nurses (Mary Dutton, Nicola Anderson and Elliot Forster) for more information or visit the website www.birmingham.ac.uk/RePROM

Thanks to funding from the Q.E.H.K.P.A., Nicola Anderson, a Senior Renal Research Nurse at the QE

Hospital, has won support from the National Institute of Health Research to conduct the next phase of this research. She will be exploring how ePROMs can be used to help patients undergoing dialysis.

It is exciting to have kidney nurses starting to lead the field in this type of work and it is notable that she has already had articles relating to her research published in medical journals (including BMJ Open and the American Journal of Kidney Diseases). She was also an invited speaker at the International Society of Nephrology World Congress 2019 in Melbourne, Australia. Congratulations to Nicola. We look forwards to hearing about her research in future newsletters.

We know from patient surveys that we must continue to find ways to improve the way patients with long term diseases are cared for. The renal research group at UHB and the partners with whom they work are fully committed to working with patients to achieve this and would be interested to hear from anyone who wants to get involved.

Dr Derek Kyte, Nicola Anderson, Sister Mary Dutton and Dr Olalekan Aiyegbusi



What is “Shared Care” Haemodialysis

This is a new service being offered by the Hospital to give more choice to Renal Patients in dealing with their condition

Shared Care means you can choose how much or how little you wish to manage your own dialysis treatment. You will be supported by nurses and healthcare assistants in the Dialysis unit to help you gain confidence with the tasks you wish to participate in.

Doing shared Care dialysis allows you to progress to Home haemodialysis should you wish. Otherwise many patients do their own Shared Care in their dialysis unit on a regular basis.

Here at Assure Dialysis Services we had a roadshow in March to promote our Shared Care programme we are setting up and also attended the Home Therapies Roadshow on 17th May at Smethwick.

We aim to train as many patients to take part in their own dialysis treatment doing various tasks from weighing themselves, taking their temperature and blood pressure right up to setting up their machine and needling their fistula using a competency-based training programme tailored to their needs.

We currently have 4 patients who are now self-caring and several more currently in training. Enabling patients to do this has resulted in them being able to fit dialysis around their lifestyle as they have flexibility to dialyse when they wish.

It has given them back control of their lives and managing their illness with patients saying they now feel they are in control of their illness and it does not control them. It has been a very positive experience for those patients taking part. We hope this will keep growing and give more patients the opportunities Shared Care can bring.

If you want more information about Shared Care, please contact Angela Ward who will be pleased to discuss this with you. There is also more information on our web page under Patient Information.

Angela Ward Dialysis Nurse. Email: Angela.Ward@uhb.nhs.uk



Thanks Geraldine and Beryl

Our gratitude to Geraldine Davies and her friend Beryl, who over time have raised well over £1000 with Book Stalls and Bric-a-Brac sales In Halesowen Precinct.

Thanks again to both of you from the Patients and the Queen Elizabeth Hospital Kidney Patients' Association for supporting us.

The Q.E.H.K.P.A. help P.D. Patients



We have recently installed a TV in the I.V. Suite in the Peritoneal Dialysis Unit. This area is where patients sit and wait for long periods while having treatment and tests.

We were asked by the staff if we could help to provide a TV in the area. Due to generous support from everyone we were able to do this. We had to get the aerial and wall brackets fitted and installed. The TV in the IV area was donated by a member of staff. Thanks to all. It's up and running.

We had previously supplied and installed a TV and new furniture in the waiting area.



In Memorium

The Queen Elizabeth Hospital Kidney Patients' Association wish to acknowledge and thank families and friends of those who have passed away and made donations. We are very sorry that we are unable to put their names in this edition of the newsletter. We have written to them. Our deepest sympathies to you all and thank you for supporting us at such a difficult time.

Patients' stories and experiences

Do you have a story you would like to share with other patients? It may be how you arranged a holiday, or how you sorted out your dialysis to be able to fit it in with your work. Ideas to make life easier dealing with haemodialysis or A.P.D. and C.A.P.D. could be useful. You may be a transplant patient, or a living donor and others will benefit from hearing how you got on.

We can post them on the website or put them in the Kidney Matters Newsletter for other patients to read. It often helps other patients and in particular patients who are new to renal issues or about to start on treatment to learn how others are dealing with it.

There are a number of stories and comments from patients on our website, so please have a look.

We will not publish your name or address with any information you may provide.

Patients' Holiday

The holiday that Sharon Pilling organises is still planned for the last two weeks in September. There have been a few minor problems in sorting out hotels and dialysis treatment and with all the uncertainty with "Brexit" this has not helped. All being well, it will be alright in the end and everyone will enjoy the holiday in Benidorm.

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 10th JULY 2019 at 7.30 p.m.

AGENDA

- | | |
|--|----------------------------|
| 1. Apologies for absence | 5. Treasurer's report |
| 2. Minutes of the last A.G.M. held on 11th July 2018 | 6. Election of Officers |
| 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.

Thanks to those who have made donations to the Queen Elizabeth Hospital Kidney Patients' Association

The Q.E.H.K.P.A thank all of you who have raised money or donated to us over recent months.

Your generosity has been very welcome and helps us continue our support for the Renal Patients and the Renal Departments at the Queen Elizabeth Hospital.

We have been able to help in many ways by supporting outings at some of the units, refreshments at special occasions and several research projects. We have several other projects we are looking into to help patients and the Hospital. Please note: If any unit wishes to organise a trip for patients please contact us and we will see what we can do to help.

If you want help in organising an event please contact us. We will be pleased to assist.

Patient Information

If you go on the Q.E.H.K.P.A. Website www.kidneymatters.co.uk you will find copies of all the U.H.B. Renal patients' 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.

Queen Elizabeth Hospital Kidney Patients' Association meetings

The Q.E.H.K.P.A. meets every month except August and December at 7.30 pm in the Faith Centre at the Queen Elizabeth Hospital on the 2nd Wednesday each month.

Everyone is welcome to come along.

Please phone Nick Flint on 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

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

Terry Jones
137 Penn cricket Lane
Warley
West Mids B65 0RF
Tel:- 07982938317