



KIDNEY MATTERS®

The Newsletter of the
Queen Elizabeth Hospital Kidney Patients' Association
OCTOBER 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

National Transplant Week

National Transplant Week at the Q.E. started on the 2nd September with the Queen Elizabeth Hospital Kidney Patients' Association, the Transplant Team and the support of the Renal Dietitians promoting the work of the Hospital in Kidney Transplantation.



The event took place in the Atrium of the Queen Elizabeth Hospital. Very many visitors to the Hospital were able to ask questions about organ donation. Some of the questions we were asked were "Am I too old to be a donor?" "Who can donate?"



The team were able to discuss these with them. We were asked many times about the new 'Opt Out' law coming in to force next year. There is more detail about this on our web page www.kidneymatters.co.uk.

It was also very interesting to meet patients who had received a kidney transplant. Some only a few weeks ago and some very many years as 20 and 30 years. This gives reassurance to those who are about to have a transplant and those who are waiting.

The K.P.A. thank the Transplant Co-ordination team for their support and the hard

work they do in supporting patients before and after transplants.

Kidney Matters - The title of our Patients' Newsletter.

We have now been able to register the name of our magazine which we have been circulating to all renal patients treated by the Q.E. for over 38 years.

We would like to point out that another charity has also started to use our name for their magazine.

We are the Queen Elizabeth Hospital Kidney Patients' Association and our aim is to support renal patients at the Queen Elizabeth Hospital. All the funds so very generously donated to us by patients and their friends is for the benefit of those patients.

All the members who give up their time to run the Association do so voluntarily and are renal patients, carers or families.

Information for new and existing patients

The Queen Elizabeth Hospital Kidney Patients' Association is a charity to support all renal patients treated by the Queen Elizabeth Hospital.

It is run by patients, carers and families for patients.

We also have a KidneyMatters website www.kidneymatters.co.uk which has lots of information.

This includes dietary advice for all renal patients. There are ideas for P.D., haemodialysis and transplant patients. There are menus for every day eating and keeping healthy, plus lots of ideas for parties and special occasions.

All this information is provided by the Hospital dietitians

On the website there are all the Queen Elizabeth Hospital Renal Patient information booklets which you can download or read on line.

The dates and details of our meetings are there which you are all welcome to attend.

Patients' Holiday

The holiday that Sharon Pilling organises is going ahead on 6-20 October to Benidorm. 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 fine in the end and everyone will enjoy the holiday in Benidorm. The K.P.A. would like to thank Sharon who organises the holiday and accompanies the patients on these holidays. The holidays encourage dialysis patients and gives them confidence to organise and arrange their own holidays in the future. *Well done Sharon and thanks.*

N.H.S.B.T. information to inform patients about cancellation of a transplant.

This is important information for all patients who are on the transplant waiting list.

NHSBT or NHS Blood and Transplant organise and allocate organs for transplantation. They have decided that if a Kidney is found that is suitable for a patient and is then allocated to a patient on the waiting list but the hospital which that patient is treated is unable to carry out the operation due to reasons of capacity i.e. Bed shortage, theatre space, staff availability, the kidney would then be offered to another unit and patient. The patient who it was first allocated to will be informed that they had a kidney offer that was suitable but was turned down by the Hospital, thus their transplant could not take place.

The patients will be asked each year if they wish to be informed or not of this situation if this happens. Patients need to give this very careful thought before they agree.

Please talk to your Transplant coordinator at your next clinic to discuss this issue and if you wish to be informed or not.

I understand this is a very very rare occurrence and Hospitals when offered a kidney for transplant make every effort to do the operation.

Special thanks to Tony

We would like to thank Tony Hale who has been a very generous supporter of the K.P.A. for a number of years. Tony after he retired from broadcasting as a radio presenter decided to do 'After dinner speaking' to local groups and was very popular at W.I meetings and similar organisation. He charged a fee for his services and very generously donated these to the Queen Elizabeth Hospital Kidney Patients' Association. Over the recent years this has amounted to several thousand pounds. Our thanks to Tony for his support.

Kings Norton Dialysis Unit

Amy Ashmore Unit Manager

On behalf of King Norton Dialysis Unit, I would like to extend a massive thank you to you and your team at the Queen



Elizabeth Hospital Kidney Patients' Association As a result of your hard work, not only have you funded a day trip for our lovely patients but you have also bought a bench for the clinic so patients can sit outside and enjoy the lovely weather whilst waiting for their transport.

Once again, a huge thank you to you all at the Q.E.H.K.P.A.

We have also raised £160 from friends and family attending the trip which is for the Queen Elizabeth Hospital Kidney Patients' Association.



In addition, we will be hosting a Clinic Raffle in the coming weeks and will be happy to donate all monies to the Queen Elizabeth Hospital Kidney Patients' Association. Once again – Thank you. It was a really great day enjoyed by all.

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

We have enclosed a £5 book of tickets. They are all cash prizes again this year. Please try and sell as many as you can.

The Draw is on the 8th January at our monthly meeting.

This is the only raffle we organise and the only time we ask everyone for their support.

All the money raised is for the benefit of Renal patients at the Q.E., the Dialysis Units, P.D. Patients, Home Haemodialysis and Transplant Patients.

All the money we receive is used to help and support the Queen Elizabeth Hospital Renal unit and renal patients. If you would like more tickets, please contact a member of the committee and we will arrange to get them to you. *Thank you for your support.*

**Queen Elizabeth Hospital
Kidney Patients' Association**

Q.E.H.K.P.A. Annual Raffle 2020

FIRST PRIZE £500
SECOND PRIZE £250
THIRD PRIZE £125
5 PRIZES of £50 & 5 PRIZES of £25

TICKETS
£1
EACH

TO BE DRAWN ON 8TH JANUARY 2020

Festive season approaches

With the festive season just around the corner there will be plenty of opportunities for family gatherings, celebrations and parties. Being a renal patient having to be careful about diets can be difficult. The Renal Dietitians have provided a very wide range of ideas for celebration foods and also tips on what you can substitute ordinary foods for food that is better for you as a renal patient.

If you go to our website www.kidneymatters.co.uk and look under dietary information, there are very many ideas to look at. All

have been provided by the Hospital. If you have difficulty looking them up or cannot download them, please ask at your unit and I'm sure the staff will help you or contact one of the committee and we will send copies to you.

Being a renal patient does not stop you enjoying these events.

A little planning can make all the difference.

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.

Amazon and the Queen Elizabeth Hospital Kidney Patients' Association

You can now select the QEHKPA as your chosen charity with Amazon.

Amazon Smile is a website operated by Amazon but with the same products, prices and shopping features as Amazon.co.uk. The difference is that when you shop on Amazon Smile, Amazon will donate 0.5% of the net purchase price (excluding VAT, returns and shipping fees) from your eligible AmazonSmile purchases.

To select the QEHKPA as your chosen charity, sign in to smile.amazon.co.uk on your Laptop, Tablet or Mobile. You will be asked to sign in your

account. The login and password are the same as your existing Amazon account. You will still see all your previous purchases on Amazon. If you do not have an Amazon Account, you will be asked to register.

On your first visit to this site you will need to select a charitable organisation to receive donations from your purchases. To find the QEHKPA enter in the box labelled QEHKPA. It will show Walsall EW as the location, that is the K.P.A. address as opposed to the Q.E. Hospital address.

If you have a short cut or link to Amazon on your device replace that link with this new Smile web page that will ensure when you select Amazon you will be on the charity web site.

When you go the Amazon home page you should see under the search bar "Supporting: Queen Elizabeth Hospital Kidney Patients Association". There is a drop-down box that will allow you to see how much you have generated. Each time you review an item you should see "Eligible for Donation", however not all items are eligible.

Should you search for an item outside of the Amazon Web Page you may find the item shows on Amazon but not on the smile version. Sign onto that page, add the item to your basket then close that page. Sign in using you Smile link and purchase the item through the Smile web page. The item will be in your basket.

TV in Ward 302 is on the way.

We have been asked by the ward Manager of ward 302 and several patients if we could provide a TV in the patient waiting area. Patients often have to spend long

periods of time waiting for their test result to come through and a TV would benefit patients and help pass the time. This seems a very worthwhile item to fund. We have now had approval from the

Estates Department to proceed with this and they will install the aerial and wall brackets (at a cost of £550 to us) and we will provide the TV.

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 were sorry we could not include their names in the last edition due to an editorial problem.

We Remember

Robert Hicken
Maurice Timms
Norman Thomas
Thomas Tranter
John Derek Whyley
Tim Forster
Michael Patrick Nolan

Our deepest sympathies to families and friends and thank you for supporting us at such a difficult time.

Thanks to those who have made donations

The Q.E.H.K.P.A. thank all of you who have raised money and 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 would like to thank the following people who have generously donated to Q.E.H.K.P.A. Jeremy Duggan, Friends of Tangent, Cindy

Rodgers, Miss J Johnson, Mrs A White, Jenny and Andy Blake, Mrs Batch, Mrs Weir, Aman Joseph, Caroline Harrington, Raymond Smith, Vince Essex, Pauline Cook, Peter Cripps, Mr Kathirgamak. Without your help we could not support patients and the Hospital as we do.

We have been able to help in many ways by supporting outings at some of the units, refreshments on special occasions and several research projects. We have several other projects we are looking into to help patients and the Hospital.

Introducing the new Manager at Aston Dialysis Unit

Aston have recently had a new Manager Elizabeth (Liz) Wood. Liz joined Diaverum in July and has been spending a lot of time getting to know the staff and patients in her care.

This is her first job in a dialysis unit, but her background has been in the care environment and understands the needs of patients with long term condition.

Her hobbies include dog walking for the charity Cinnamon Trust which is the only UK charity to provide pet care for terminally ill and elderly patients.

When I met with Liz she said she has lots of plans to help make the time patients spend at the unit as pleasurable as possible and that her door was always open whenever patients want to have a chat. We look forward to assisting her and supporting her patients.



Patient Information

If you go on the 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 a new information booklet about care and treatment following a transplant.

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.

Flu vaccination advice for dialysis/kidney transplant patients

Saehara Khan, Pharmacist Cathy
Richardson Advanced Nurse Practitioner
Queen Elizabeth Hospital, UHB

The flu vaccination is available every year on the NHS to help protect those at risk of flu and its complications. The best time to have a flu vaccine is in the autumn, from the beginning of October to the end of November.

Why should have I the flu vaccine?

Children and adults with weakened immune systems, such as those who have had a kidney transplant and are taking anti-rejection medication, or an underlying health condition are at greater risk of developing potentially serious complications of flu, such as pneumonia (a lung infection), so it is recommended that they have a flu vaccine every year to help protect them.

People in close contact with kidney transplant patients are also eligible to have the flu vaccination.

How effective is the flu vaccine?

Flu vaccines that have been licensed recently in England have been thoroughly tested before they're made available, and have been used in other countries with a good safety record.

Flu vaccine is the best protection we have against an unpredictable virus that can cause severe illness and death among at-risk groups, including those with a kidney transplant or an underlying health condition.

Studies have shown that the flu vaccine will help prevent you getting the flu. Please note that it takes about two weeks for the immune system to fully develop a response to the vaccination.

It will not stop all flu viruses and the level of protection may vary, so it's not a 100% guarantee that you'll be flu-free. But if you do get flu after vaccination, it's likely to be milder and shorter-lived than it would otherwise have been.

There's also evidence to suggest that the flu vaccine can reduce your risk of having a stroke. Over time, protection from the injected flu vaccine gradually decreases, and flu strains often change. So new flu vaccines targeting the flu strains that are most likely to cause flu are produced each year, which is why people that are advised to have the flu vaccine need it every year. The flu vaccine CANNOT give you flu.

Side effects:

Serious side effects of the injected flu vaccine are very rare. You may have a mild fever and aching muscles for a couple of days after having the vaccine, and your arm may be a bit sore where you were injected.

Which type of flu vaccine should I have?

There are several types of flu vaccine. You'll be offered the one that's most effective for your age:

adults aged 18 to 64: quadrivalent injected vaccine – the vaccine offered will have been grown either in eggs or cells (QIVe or QIVc), which are considered to be equally suitable
adults aged 65 and over: adjuvanted trivalent injected vaccine grown in eggs (aTIV) or a cell-grown quadrivalent injected vaccine (QIVc) – both vaccines are considered to be equally suitable.

Please note that those who have received a kidney transplant must only have inactivated vaccinations. The vaccines listed above are all inactivated and therefore safe to have.

You should avoid vaccination if you have had a serious allergic reaction to a flu vaccine in the past.

Talk to a GP, practice nurse or pharmacist for more information about these vaccines.

Where can I have the flu vaccine?

You can have your NHS flu vaccine at your GP surgery, a local pharmacy offering the service or your midwifery service if they offer it for pregnant women.

If you have your flu vaccine at a pharmacy, you do not have to inform a GP. It's up to the pharmacist to do that.

I have young children – can they have the flu vaccine?

Children aged 2 to 17 in an eligible group are offered a LIVE attenuated quadrivalent vaccine (LAIV), given as a nasal spray. Side effects of the nasal spray vaccine may commonly include a runny or blocked nose, headache, tiredness and some loss of appetite.

Children aged between 6 months - 2 years old and in a high-risk group for flu and children aged 2 years or above in whom LAIV is contraindicated are offered injected the egg-grown quadrivalent influenza vaccine (QIVe).

There is a theoretical potential risk of transmission of the LIVE attenuated flu virus in LAIV to very severely immunosuppressed contacts such as new kidney transplant patients, for one to two weeks following vaccination. In the US, where there has been extensive use of LAIV, there have been no reported instances of illness or infections from the vaccine virus among immunocompromised patients inadvertently exposed. Where close contact with very severely immunosuppressed contacts (for example household members) is likely or unavoidable however, consideration should be given to using an appropriate inactivated flu vaccine instead.

If you feel ill after exposure to a child who has been recently vaccinated with the LAIV nasal spray please seek medical attention.

If further advice or information regarding this if needed. If you are a Kidney transplant patients:- please call:- Q.E. kidney transplant team. If you are a Dialysis patients please call:-Your dialysis centre

**Contacts for the
Q.E.H.K.P.A.
Please phone, write or
email if you need
information or help**

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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:-

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My Name.....
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.....
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No longer a patient at Q.E.

Please do not send

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