

# Kidney Matters<sub>®</sub>

The Newsletter of the Queen Elizabeth Hospital Kidney Patients' Association July 2023

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## 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 2700 Renal Patients treated by the Q.E. Hospital

## Welcome to another edition of Kidney Matters®

We want to keep you up to date with what we are doing. We hope you enjoy reading it.

## Your help is required – A new project investigating routine blood testing in hospital for inpatients.Led by Dr. Tanya Pankhurst

A team of researchers from UHB are looking to conduct research into the number of blood tests patients undergo during admissions to our hospitals. In particular, it aims to compare the number of blood tests ordered automatically by our computer systems compared with the number ordered by clinicians.

Sometimes, for example when certain drugs are prescribed or when previous results are abnormal, our computer system automatically requests blood tests according to a collection of pre-set rules. We want to ensure that these rules are set to ensure the best possible balance between ordering blood tests when they are needed, but without ordering unnecessary blood tests which is both uncomfortable for patients and costly for the NHS.

We know that, as a group, patients admitted to our renal wards tend to undergo blood tests some of the most frequently of all our patients, so your feedback will be particularly valuable in helping shape the experience of future patients in our hospitals.

We expect that the results of this research will not only directly enable changes to the rules within our hospitals but will be widely applicable to other hospitals also.

If you are willing to share your feedback, we would be very grateful if you could complete our short survey by clicking the link below or type this into your internet browser.

#### **CLICK HERE TO GO TO SURVEY**

Dr. Tanya Pankhurst
Consultant Nephrologist
Director of Digital Healthcare
Chief Clinical Information Officer

### News from the Birmingham Transplant Games Team

We have 37 competitors taking part in the Westfield Health British Transplant Games which take place from 27th to 30th July in and around Coventry.

Our 37 competitors consist of -

- 9 Kidney patients
- 1 Kidney & Liver patient
- 1 Double Lung transplant patient
- 18 Liver patients
- 4 Heart patients
- 4 Stem Cell patients.

Last year as you may know there were 23 of us who took part in the Games in Leeds. Each one of us gained at least one medal each and we also topped the medals table. It would be really great to repeat this quest at this year's Games, especially. Considering that this is the biggest number of competitors taking part for our team since the Birmingham games in 2018 it was great to see the team in your newsletter. There were 13 of our team competitors who took part in the World Transplant Games in Perth, Australia. They returned with 34 medals between them.

I will let you know how the team get on on my return from Coventry.

**Best Wishes** 

Martin Searle



Last year's team

## Annual Holiday for Dialysis Patients

It has been over 3 years since we were able to support the annual holiday for dialysis patients due to the covid problems. It is hoped that next year we may be able to support the Dialysis Holiday again, which many patients enjoyed so much.

We will keep you updated on this and lets hope we can return to normal as soon as possible.

Our thanks to Sharon Pilling for organising these holidays over the past years. They have been very enjoyable and beneficial to many patients. It has given many patients the encouragement and confidence for them to organise their own holiday which they didn't think they could manage by themselves.

Leigh Allen from Worcester has organised a fun run with his friends and family to raise funds for the Queen Elizabeth Hospital Kidney Patients' Association. This is his story and how to support him.

### Story from Leigh

Hello and welcome to our fundraising page. We are running in memory of our uncle/cousin a recipient of multiple kidney transplants.

There are 5 of us running: Leigh, Mollie, Isabel, Henry and Harry

We are taking part in the Worcester 10k run on September 17th 2023

Not all of us have run 10k before so this is a challenge. However something we are looking forward to doing in order to raise awareness of this charity. Hopefully making a difference for future kidney transplant patients.

The QE kidney patient association was very important to Jeremy and therefore we would

like to continue his appreciation of this group through raising some much-required donations. It doesn't matter how big or small the contribution, every donation makes a difference to those people who require future transplants. Thank you from all of us. Thanks for taking the time to visit my JustGiving page. Donating through JustGiving is simple, fast and totally secure. Your details are safe with

totally secure. Your details are safe with JustGiving - they'll never sell them on or send unwanted emails. Once you donate, they'll send your money directly to the charity. So it's the most efficient way to donate - saving time and cutting costs for the charity.

Please copy or type the following into your internet browser to go to Just Giving page to support Leigh.

#### CLICK HERE TO GO TO JUST GIVING PAGE

# 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 and years.

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

Thank you all again.

### Some of the ways we are supporting the Hospital and Patients.

#### Get together for Home Haemodialysis patients.

The dialysis staff at Smethwick unit have organised a Sunday get together for Home Haemo Dialysis Patients and Carers on the 23rd of July.

This will be a nice opportunity for patients to meet each other at a social occasion and away from the dialysis unit.

This has been funded by the Queen Elizabeth Hospital Kidney Patients' Association and the Smethwick Home Haemodialysis Fund.

#### The New Birmingham Transplant centre

The Queen Elizabeth Hospital is opening a new Transplant Centre. This will cover all transplants at the Q.E. in one area, Kidney, Liver, Heart and Lung all with their own specialists and equipment in one area.

The Queen Elizabeth Hospital Kidney Patients' Association has committed £60,000 towards this project.

#### **Exercise Balls**

We are also continuing to provide the Exercise Balls for the nurses to give to patients to help with their fistulas.

#### The joy of volunteering.

This is a story from a patient who decided to help Kidney Research UK to help other patients.

Maria Buckley started volunteering for Kidney Research UK as a community ambassador after she had a kidney transplant in 2020, and the 72-year old from Milton Keynes says it's been a "very fulfilling" experience.

In her role, Maria talks to people in her local area about her own journey with kidney disease, and she's the first to admit that she gets just as much out of it as they do. She says, "A lot of people say that I'm helping people by doing this but I also learn so much myself. I think it benefits me more than others."

Maria was diagnosed with diabetes in her 30s and over the years her renal function deteriorated to the point where she had to start dialysis in 2019. This continued for 18 months before she received a kidney transplant in June 2020 and Maria is now passionate about educating others because she feels she didn't have access to much information when her kidneys started to fail.

Talking about how her outlook changed after her transplant, Maria says, "The surgery extended my life. It was the best gift in the world and the whole experience enlightened me. After my recovery, I decided to help raise awareness of kidney health, and to raise awareness about kidney disease. I joined different kidney patient support groups to learn and to get peer support and I also took part in research projects. And then I became a community ambassador for Kidney Research UK and now I organize talks in local community groups. On World Kidney Day this year I organised an information stand in the kidney clinic in Milton

Keynes University Hospital, and chatted to people there, letting them know about the charity's new Kidney Kit and other activities."

Maria, who is also on the readers' panel for the charity (which involves helping to create accurate and relevant content for those suffering with kidney disease), has found that sharing her story has a great impact on her audience. She says, "When I do the talks, I discuss the risks, the symptoms, and how to keep the kidney fit. And I talk about my own journey. So far all of my talks have gone well and occasionally I receive a donation from attendees for the charity."

She says, "I get a lot of positive feedback from people who come and they'll say things like, 'I'm so glad you came, I learned so much. I understand things better now.' I would definitely encourage others to volunteer as it really widens your horizons and helps you understand other people's difficulties and have empathy for them. Being a volunteer is all about humanity, empathy and strength and it's helped me to be a better version of myself." Get involved. If you're interested in joining Team Kidney and representing Kidney Research UK as a volunteer, email volunteer@kidneyresearchuk.org or

call 0300 303 1100

Or you may wish to help with the local group the Queen Elizabeth Hospital Kidney Patients' Association

Contact Nick Flint via email <a href="mailto:qehkpa@gmail.com">qehkpa@gmail.com</a> for more details.

Please visit our web page <a href="www.kidneymatterrs.co.uk">www.kidneymatterrs.co.uk</a>. There are some very useful ideas for menus and food ideas for those on special diets. Thanks again for all those who have supported us.

We would also wish to pass our deepest sympathies to those families who have sadly lost a loved one and thank them for their very generous donations in their memory.

If you wish to contact the Queen Elizabeth Hospital Kidney Patients' Association our email address is <a href="mailto:qehkpa@gmail.com">qehkpa@gmail.com</a> or Phone Nick Flint 07720597468