

# **KIDNEY MATTERS**

The Newsletter of the Q.E.H.K.P.A. February 2019 **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

# **Lucky Winners of our Christmas Draw 2019**

Congratulations to the lucky 13 who have won this year's K.P.A. raffle. This is the list of winners. All winners have been notified and results are also on our website.

All the money we raised will be used for the support of the Renal Patients and the Hospital Renal Unit. This includes all those who dialyse at any of the 11 Q.E. dialysis units around the area, those at home and on CAPD.

This is an annual raffle and is the ONLY time we directly ask all Renal Patients for their support.

We thank you for supporting us this year. We know you receive many requests to support other charities, but this one is for the benefit of Renal patients and the Queen Elizabeth Hospital Renal Department.



NUMBER	NAME	PRIZE
04326	J. WILLIAMS	£500
03814	K. HART	£250
13243	S. BEGUM	£125
07040	D. METCALF	£50
05972	P. WATSON	£50
05159	P. TAYLOR	£50
05625	S. MARGRETT	£50
00075	S. MIDDLETON	£50
12001	M. ROSE	£25
03781	I. PARKER	£25
05320	J. STEVENS	£25
01334	J. PALMER	£25
12397	J. SPENCE	£25



The draw took place at the monthly meeting on January 10<sup>th</sup>. We had two nurses from the renal unit, Rupinder Kaur and Veronica Fleming to draw the winning tickets.

We sold £3293 worth of tickets, which is an amazing amount and thanks to all those who very generously supported us this year.

Thank you all.

### Q.E.H.K.P.A. helps C.A.P.D. Unit and Dietitians

The K.P.A. have been asked to provide a TV for the I.V. Suite in C.A.P.D. as patients have to sit for long periods of time during tests and treatment. We are in the process of having this installed during the next few weeks. It may even be up and running when you read this article. We hope this helps patients pass the time.

Before Christmas the renal dietitians asked us to provide diet sheets with festive food and eating ideas for patients. These proved very popular as they give ideas not only for Christmas but other festive occasions throughout the year. If you would like copies they are available on our website to download.

If you don't have a computer, please contact us and we will send you copies or ask your renal dietitian for copies.

The K.P.A. are able to support these and other projects because of the hard work and generosity of all those who support us with donations and fund-raising events throughout the year.

# **Annual Patients' Holiday**

Planning is under way for another patients' holiday organised by Sharon Pilling. It is expected to be at the end of September as in previous years. Date and details will be available soon.



This is a great way for dialysis patients to be able to have a holiday and help build confidence for them to organise their own holiday in the future. Two members of staff generously give up their time to organise and look after patients for the two-week holiday.

The K.P.A. support the holiday by funding the staff members.

If you are interested and wish to go, please contact Sharon Pilling on 07843433808 or email Sharon.pilling@uhb.nhs.uk and she will keep you informed. Numbers are limited, so please book early.

These are some photos from last year. Everyone had a great time.

#### **Red Fistula Wrist Bands**

The Q.E.H.K.P.A. have stocks of fistula wrist bands. They are RED with white lettering warning **FISTULA**. They are free for Q.E. patients.

Please ask at your unit for one. If they don't have them ask a staff member to contact the Q.E.H.K.P.A. and we will send some to them. If you contact us directly we will send one to you.

There are 3 sizes small, medium and large.

Our contact details are on the back page.



# Fundraising for the Q.E.H.K.P.A.

The support that the Q.E.H.K.P.A. receives from patients, carers and families is tremendous. We would like to thank everyone. Without your support the projects we fund, the outings, research projects and equipment, would not be possible.

Remember all the money that is donated to and raised by the Q.E.H.K.P.A. is used to support Q.E. Renal Patients and all the Renal departments at the Q.E. Hospital. The Q.E.H.K.P.A. have no paid staff or expensive offices. It is run by patients, families and carers.

These are some of the ways support has been given to the K.P.A. in the last few months. Mrs Masters again made and sold Christmas cards and gifts and raised £250. This has become an annual event, well done. A lot of time goes into making all the items. Thank you.

The Shelfield Male Voice Choir named us as their charity of the year. They had organised several concerts during the past year and held a Christmas Carol Service in December. They presented us with a cheque for £1000, plus another anonymous donation of £500. They wanted to support us and the Hospital as their Conductor's wife is a Renal Patient and recently had a transplant at the Q.E.

Stephen Betteridge is supporting us by doing 14 days trekking around the Annapurna Region of the



Himalayas in Nepal where some of the highest mountains in the world are found. January is the coldest period in the region with temperatures often falling below freezing at night. Dates he is there from are 14 January 2019 to 30 January 2019. "I am aiming to raise funds for the Queen Elizabeth Hospital Kidney Patients Association in memory of my Mother-in-Law who sadly passed away with renal failure in 2015. The staff, nurses and doctors were extremely caring, helpful and supportive throughout her illness."

"I would like to raise money to support the fantastic work throughout the hospital and especially the support provided by the Queen Elizabeth Hospital Kidney Patients' Association."

To date Stephen has raised £3250 for the K.P.A. Our thanks to Stephen and all those who supported him. Very well done and enjoy the trek.

#### Surprise visit at November meeting.

At our last meeting, we had a visit from Mr Les Woodley and his brother Brian. They gave us a very interesting talk about their experiences as a renal patient. Brian had donated a kidney to Les 12 years ago and both have done very well. It was a life changing event for Les. Les told us how pleased and impressed they had both felt about the care and treatment they had received and continued to receive from the Queen Elizabeth Hospital. Les was also very pleased with the work the Q.E.H.K.P.A. was doing to help patients. To show his appreciation he then donated £1000 to help us continue our work. In the picture from the left:-Terry Jones V-Chairman, Brian, Les and Nick Flint Chairman.



### Chilli and Kidney Bean Supper raised £1185

On Monday 12<sup>th</sup> November 2018, Clent Club member Bea Jones donated one of her kidneys to her friend Caroline Meluish. On Friday 14<sup>th</sup> December, just one month later, both ladies attended a fund-raising event at Clent Community & Social Club for the Kidney Transplant Unit at the Queen Elizabeth Hospital.

Members were invited to cook a Chilli and 11 of them took up the challenge. Each chilli could be to their own recipe but MUST include 'kidney' beans. Members and friends then bought the Chilli for a delicious warming supper in the Club.

A raffle was held and following a donation from the Clent Gents Club of £600, a total of £1,185 was raised on the night.

Thank you to everyone who cooked a Chilli, purchased a bowl of Chilli on the night or bought a raffle ticket. We couldn't have done it without you!

Thanks to all in Clent who supported them. Best wishes to Bea and Caroline.



# Chris Millinson running the Birmingham Half Marathon



Chris decided to run a marathon to raise money for the Renal Units at the Q.E and New Cross Hospital. Both his parents have had renal problems. His father was treated at the Q.E. in Birmingham and his mother at the Royal Wolverhampton Hospital. He wanted to help both units.

Chris raised £1300 which was split between the two charities. On the 25<sup>th</sup> January Chris presented a cheque to the Renal Unit at Wolverhampton.

Thanks Chris and well done and thanks for your support.

### More generous donations.

We also thank all those who have supported the K.P.A. with donations. These include, Miss J Johnson, Mr and Mrs Luhar, Rodway Family Trust, Mr and Mrs Blake, Mr and Mrs Gane, Mr Johal, Mr and Mrs Bevin, Mr J Duggan and Alice Brown. We also thank those who are making regular donations by Direct Debit and Paypal. All your support is invaluable to us. Thanks again everyone.

#### Update on research project to extend the life of a Donated Kidney before being transplanted.

This is a major piece of research which the K.P.A. has funded. It is hoped that the outcome will be that deceased donor kidneys for transplantation could be kept several days before being transplanted. This would lead to better matching, planned surgery and improved outcomes for patients.

#### This is an update by Mr Jay Nath.

The research support grant from transplantation.

early promising results.

metabolic decelerator during this preservation time. Transplantation, Queen Elizabeth Hospital Preliminary studies have shown that in the presence of

the such compounds, the metabolic demands are greatly Q.E.H.K.P.A. has been instrumental in maintaining the diminished, even in highly non-physiological conditions. kidney transplant research programme in Birmingham Over the next 12 months, we aim to determine whether with the overarching aim of improving and prolonging the a metabolic decelerator compound can be used in time a deceased donor kidney can be kept before substitution for hypothermia to decrease kidney energy requirements during storage. Whilst the current practice As elaborated in the previous newsletter, using of storing organs at low temperatures does limit novel NMR spectroscopy techniques, we have recently metabolism and therefore increase the time the organ demonstrated the metabolic benefits of oxygenation can be kept out of the body, there are deleterious during the kidney storage period. This provides consequences of cooling and then re-warming organs mechanistic evidence to underpin ongoing multinational these fragile organs, with the ischaemia reperfusion human transplant studies which have demonstrated injury a major limiting factor of transplantation. Thus, if similar metabolic effects to hypothermia can be Subsequent laboratory work has utilised an provoked using pharmacological mechanisms, it could established cell line model of machine perfusion to result in a major improvement in organ storage practice. investigate a series of compounds that act as a Mr Andrew Ready, Mr Jay Nath. Department of Renal

#### In Memorium

Our sympathies go to the families and friends of loved ones who have sadly passed away.

We remember: -Kenny (Kipper) Fisher who passed away in October, he had been a renal patient for 15



years. He and his wife had been on several patient holidays. He was a very keen fisherman and will be sadly missed by all his friends and family. The family wanted to support the Q.E.H.K.P.A. and the Hospital as they and Kenny had been so appreciative of the help and support given over the years by both. They raised £2000 in his memory which will help us to continue our work with the Patients and Renal unit.

We also remember Gerald Broderick, Christopher Osbourne, Sam Williams, Leslie Masters, Brian Howell and Raymond Saunders. We thank you for the donations in their memory.

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

#### **Dialysis Units enjoyed Christmas festivities**

In the weeks leading up to Christmas many of the dialysis units organised buffets over a couple of days for patients. The Q.E.H.K.P.A. were pleased to be able to fund these at the units and our thanks to the staff who organised them.

If any of the units wish to organise similar events for patients to mark other occasions during the year the Q.E.H.K.P.A. are always looking at ways to support patients.

The K.P.A. would also like to support in a similar way Home Dialysis patients and C.A.P.D. Patients. A "Get Together" might be an idea. If anyone has thoughts on this please contact us.

# World Kidney Day Thursday 14 March 2019

Why not come along and meet the Q.E.H.K.P.A. on World Kidney Day.

We will be in the Atrium of the Queen Elizabeth Hospital from 9.30am until 3.30pm. There will be members of staff from the renal units and you will have the opportunity to talk and find out about renal care. The dietitians will also be on hand to give advice on healthy eating and keeping well.

Look forward to meeting you all.

#### **Patient Information**

If you go on the Q.E.H.K.P.A. Website <a href="www.kidneymatters.co.uk">www.kidneymatters.co.uk</a> 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. meet every month except August and December at 7.30 pm in the Faith Centre at the Queen Elizabeth Hospital on the 2<sup>nd</sup> Wednesday.

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, 4<sup>th</sup> Floor Nuffield House, Mindelsohn Way, Edgbaston, Birmingham B15 2TH

My NameAddress	No longer a patient at Q.E.
Post Code	Please do not send

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

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

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