



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. June 2016
Visit www.kidneymatters.co.uk

Registered Charity No.513446

Queen Elizabeth Hospital Kidney Patients' Association

The Patients' Association for all Renal Patients treated by the Q.E. Hospital
Patients on HHD, Transplant, and PD

Dialysis Units at Aston, Great Bridge (Tipton), Woodgate, Kings Norton, Smethwick, Sparkhill, Redditch, Worcester, Kidderminster, Hereford, Llandrindod Wells, and U.H.B.

Golfers support the Kidney Patients Association.



Tom Simons, pictured in the middle, is Captain of Shirley Golf Club, decided to nominate the Q.E.H.K.P.A. as his charity for his year in office. On 12th May he organised his Captain's Day Golf competition and about 80 players turned out to take part.

The day went very well with brilliant sunshine to make the day perfect. The total amount raised will not be known for some time, as there are other events planned during the rest of his year as Captain.

Tom chose the Queen Elizabeth Hospital Kidney Patients' Association because he is a renal patient treated by the Queen Elizabeth Hospital and successfully had a transplant from his wife 3 years ago. This has turned his life around, and he is now able to continue his life as it was before.

The K.P.A. would like to thank Tom for his support and wish him and his wife a very long and healthy future.

Young renal patients enjoy Go-Karting



Mark Thompson who supports the young renal patients at the Hospital organised a day of Karting for the patients last December. The K.P.A. was able to fund the trip due to the generosity of all those who support our charity.

These types of activity are very important for the young patients, as it gives them the opportunity to meet other patients outside the Hospital. We hope to be able to arrange another event later in the year.

K.P.A. meetings are held at the Queen Elizabeth Hospital on the 2nd Wednesday of each month at 7.30 pm in the New Faith Centre. Please check our web site or phone a committee member in case of a change of date.
EVERYONE IS WELCOME. SUPPORT YOUR K.P.A.



The K.P.A. supporting another major research project for Renal patients.

The Q.E. Renal Unit is now collaborating with a research team at the University of Birmingham on an exciting new project.

Professor Mel Calvert and Dr Derek Kyte are leading research in the field of "Patient Reported Outcomes" (PROMS). They are now working closely with Professor Paul Cockwell, Sister Mary Dutton and the renal research team developing accurate ways of measuring PROMs in patients with Chronic Kidney Disease. In a nutshell, PROMs look at measuring outcomes that matter to patients, for example, symptom effects, physical factors, mental health, social function and general wellbeing. Whilst recognised as important, these haven't been the traditional outcome measures that clinicians have focused on in their research.

With the generous support of the Queen Elizabeth Hospital Kidney Patients' Association, we are now able to offer a new nurse academic post to continue this field of research examining PROMs in patients undergoing dialysis. This person will work closely with Mel and Derek and be working towards higher academic qualifications. This is an exciting development and is an indicator of the high level of research already delivered by the UHB renal research team that such a position can be offered.

The project is expected to last 2 years and the K.P.A. have committed £40,000 to this major research which will benefit renal patients treated by the Q.E.

Sister Mary Dutton U.H.B.

What is Renal Peer Support?

Peer support provides kidney patients with practical, emotional and social support. It gives kidney patients an opportunity to chat and meet with an experienced kidney patient, who understands what you are going through.

Who are the Peer Supporters?

Peer supporters are patients or carers who have first-hand experience of Chronic Kidney Disease (CKD). They are unpaid volunteers and are of different ages and backgrounds and have a wide range of experiences. They have trained to provide support to fellow kidney patients. They also have had a Disclosure and Barring services check (DBS). They also have been approved and undertaken mandatory training by Hospital Volunteer Services.

Annual Get together

On 9th March 2016 we held an annual get together meeting for Peer Supporters, a very informal group meeting with refreshments. It was a thank you from the CKD Community Support Team for the continued support from our long standing Peer Supporters and to welcome new Peer Supporters. The group of seven Peer Supporters felt as a whole that they were a little under used and that it needed more promotion of the Peer Support Service to renal patients. This also may encourage new volunteers to come forward and help as Peer Supporters.

When asked why I wanted to be a peer supporter?

Comments such as:

- ◆ To pass on my experience and knowledge. Hopefully others can take some positivity from my experience.
- ◆ To pass on things you can do to improve quality of life.
- ◆ To help other patients and support them.
- ◆ Having been on the receiving end of dialysis and now received a transplant, peer support was a way of saying thank you for the kindness and support that I received.
- ◆ Sharing information.

You may find out how to become a Peer Supporter or ask for support from a Peer Supporter by contacting the CKD Community Support Team on 0121 627 5752.

Recent Donations

The K.P.A. recently received a bequest from Ms Richardson who sadly passed away last year. She was a renal patient at the Queen Elizabeth Hospital for many years and always spoke very highly of the staff and the treatment she received at the Hospital.

In gratitude of this she very generously left £10,000. to the Queen Elizabeth Hospital Kidney Patients' Association to enable us to continue our work and support to the patients and the Hospital. Thank you

We also received £1300 from a family of a transplant patient. *Thank you for your generosity.*

We again thank Mr Hale who has continued with his After Dinner Talks to clubs and associations. We have had several cheques from him and he is very generously donating all his fees for the coming year to the K.P.A.

We have also had donations from Jenny Gillies, Mrs Kaur, Dr. M Ware, Brendon and Margaret Geratty, Vera Masters, Mr & Mrs Hamer, Mr & Mrs Insley, Dave & Nikky Marriott, Dr. P Matthews and SSP staff Charities.

In the photo is Kloe Douglas (Terrier) who is the granddaughter of one of the Aston Dialysis Unit patients, Clifton Douglas, who passed away before Christmas.



Kloe did a sponsored boxing bout and raised £300. She wants this to go to the K.P.A. to help fund a summer trip for Aston patients later this year.

The K.P.A. wishes to thank everyone who has made donations to our Association

World Kidney Day 10th March 2016



World kidney day gave the K.P.A. the opportunity to promote to patients and the public what we try to do for renal patients and the Queen Elizabeth Hospital.

All types of treatments were on display:- Haemodialysis, Home Dialysis, Peritoneal Dialysis or P.D overnight treatments and Transplantation. The K.P.A. were supported by staff of the Hospital and we were there to talk to patients and families or people who were interested in renal issues. The Dietitians also had displays about healthy eating and ways to help prevent the on set of renal conditions and diabetes. Members of the Renal Research Team were also on hand to talk about the work they were doing and the future of treatments and how we had supported them.



We signed up very many people to the Organ Donor Register. We had many questions about this and lots of interest particularly those interested in live kidney donation to friends or family.

The K.P.A. wish to thank all the renal departments for the hard work making the day a success.

News from the K.P.A.

The Queen Elizabeth Hospital Kidney Patients' Association has provided head phones for patients on dialysis at the Hereford and Aston units. This will help patients pass the time while on treatment. We have also purchased "massage soft balls" to help patients who have had fistulas. These help with the exercising of the hand and fingers to improve blood flow after surgery. Smethwick unit has started a library so patients can borrow a book to read while on dialysis. The K.P.A. has also funded art materials so patients can enjoy drawing or painting to help pass the time on dialysis.

We have funds available so we would welcome ideas from staff and patients on how we can support patients and the Hospital.

THE Q.E.H.K.P.A. SUPPORTS RENAL PATIENTS AND THE HOSPITAL

Patient Transport- update

The K.P.A. is continuing its involvement with the commissioners regarding the new proposed Patient Transport Contract which will be introduced next year. It is hoped that some of the new proposals will be introduced sooner. We are working hard to insure that renal patients' needs will be met in the future and that transport for them will improve.

The new proposals are looking good. Patient collection times for inward and outward journeys will be within NICE guide lines. No more than 30 minutes waiting. Text/email/phone messages to be sent to patients when the transport is 15 minutes away from collecting you from home. Options to use other methods of transport ie taxi or community transport are being looked into. Promote the use of the Healthcare Cost Travel Scheme (HTCS) where some patients on benefit can claim the costs of providing their own transport to and from treatment.

We are optimistic that the new proposals will meet the needs of all the patients who need to have patient transport.

CCGs are keen to hear views from patients about accessing the HealthCare Travel Costs Scheme which provides assistance to people on low incomes. Eligible patients can qualify for on the day reimbursement or make a postal claim.

Have your say. Go to:- <https://www.surveymonkey.co.uk/r/ZNK8WZT>

Or visit our web site www.kidneymatters.co.uk

Letter from a patient

Dear Editor

I have just received my copy of "Kidney Matters" and I would love you to be able to print in a future newsletter how very much we appreciate all the time and effort and the friendly manner we experience every time we visit the C.A.P.D. department. For over 5 years now and we are still made to feel special. The sisters, nurses and co-ordinators have always given us their undivided attention and advice whenever we've asked for their help. I know all other patients feel the same way, that we're all greeted like we're family. The "New Look" reception area together with the newly refurbished corridors have made a real difference to a brighter more welcoming feel. I'm sure other patients appreciate the efforts that's been made. So a huge thank you to all those wonderful staff members of C.A.P.D. you are very much loved by us all.
Hazel Vanstone.

The K.P.A. were very pleased to be able to fund the new furniture in the department, it has made a big difference to the patient's' experience. Thanks to all who supported the Queen Elizabeth Hospital Kidney Patients' Association to make this possible.

Patient Information

There are now over 50 topics on Patient Information. The booklets are all produced by the Q.E. and are available on our website to download. Just go to www.kidneymatters.co.uk

Also you will find lots of information on healthy eating for dialysis patients, all the information is from the renal Dietitians at the Q.E.

For more dietary information contact your unit dietitian.

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 13th JULY 2016 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 8th July 2015 | 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 on behalf of the Association **Joan Ingram, Secretary***

Claire Hodson. Aston Dialysis Unit



It was with much sadness that we pay tribute to Claire Hodson.

Claire was a member of the staff at Diaverum Dialysis Unit, Aston. Claire passed away after a short illness in January. She supported the patients at the unit and was there for them when ever they needed help. She will be sadly missed by all patients and staff.

Apology

I would like to apologise to Mr Barry Gane whose name was listed "In Memoriam" in the February Kidney Matters, This was an error on our part.

We are very sorry for any distress caused. On behalf of the K.P.A. and myself please accept our apologies.

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 to help us continue our support for patients and the Hospital in memory of loved ones.

We remember Kate Read, Gordon Morrison, Miss Antionette Terrott and Gordon Henn.

Our thoughts are with the families at this sad time.

Many people have donated to the Queen Elizabeth Hospital Kidney Patients' Association using their mobile phone. It's a very easy way to help us. If you would like to help

Text **KDNY11 £3 to70070** and this would donate £3 to the K.P.A.

You can choose to donate £1, £2, £3, £5, or £10. by changing the amount in the message.

Thank you for your support and thanks to those who have already donated.

Donations by Cheques

Will you please make all cheques payable to Queen Elizabeth Hospital Kidney Patients' Association or Q.E.H.K.P.A. Money can be ring-fenced for a specific purpose or unit.

Do you still wish to receive this newsletter?

If you **DO NOT** wish to receive this newsletter, please let us know by contacting:-
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

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