



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. October 2010

Registered Charity No.513446

Visit www.kidneymatters.co.uk

Queen Elizabeth Hospital Kidney Patients' Association



Dawn McPake goes to Cardiff

The Renal unit at the Q.E. said a fond farewell to Dawn. She has decided to move on and further her career at Cardiff Hospital after 24 years with the Q.E.

Dawn said "I have a new post that I will start in September in Cardiff. It is still within transplantation but it is for a pancreas transplant programme. It's a lovely job for me as it is a new programme and I will be involved with patients at an early stage of being referred for a pancreas transplant right through to seeing them in clinic post transplant. So very similar to what I do at the Q.E., and of course many of them will receive their new pancreas with a new kidney. We may even be having patients from Birmingham that are on the Welsh border".

"I don't think I'll have a chance to say goodbye to everyone during the time left. The relationship between the team and recipients is a very unique one and I will be very sad to say goodbye to so many people that I have had the privilege to come to know over the years".

Dawn will be greatly missed. Many of us have known Dawn for very many years. She has supported many of us through very difficult times and her dedication and support has been appreciated. We all wish her well for the future.

K.P.A. Grand Christmas Draw.

Those who receive the magazine through the post will find £5 worth of raffle tickets. This is our major fundraising event of the year and we have very good prizes to be won. Please try and sell the tickets, if you require more tickets please e-mail or phone me Nick Flint or Len Ingram and we will be very pleased to supply as many as you need. Our contact details are on the back page of the magazines.

A very generous anonymous donation

You can imagine the surprise when our Treasurer opened the post one morning to find a cheque for £5000, yes that is right £5000. It had been sent by a family with the request that their names be kept secret and the money to be used for renal research. We have several projects that are being looked into and we will respect their wishes.

The K.P.A. are extremely pleased to be supported this way and our thanks go to them.

Thank you very, very much.

Renal Patients move into New Hospital

Preparations are well under way for the renal unit to move into its new home.

Patients, families and carers are invited to come and look round the new unit on Thursday 21st October between 2pm and 5pm on ward 301, the new name for the Dialysis Unit. The aim is for patients and families to get to know the layout and details before the move.

The move will take place overnight starting at 10pm on Tuesday 16th November. Inpatient wards move on Wednesday 17th November.

The acute unit, currently North 4 Dialysis, and the Chronic unit (R.D.U) are moving to ward 301.

For 12 months the old R.D.U will remain open until a new unit at Spark Hill is opened in August 2011. The majority of patients that remain in the old R.D.U will then transfer to the new unit in Spark Hill.

Gill from Burntwood Organises a Pop Star Night



On Fri 18th June my family and I held a pop stars evening. We were supported fantastically by family and friends and friends of friends!

We managed to obtain some really good raffle prizes including a day at Eden day spa, vouchers for the Fairlawns Hotel, Terrace restaurant and Frankie and Benny's to name a few.

We danced the night away and everyone said they had had a wonderful evening and they wanted to know when the next one would be!!

Our thanks go out to all who helped including the school and DJ Paul who kindly discounted their charges.

Our thanks to Gill for organising this event which raised £587, a really fantastic amount. Thanks from the K.P.A.

Fundraising by the K.P.A.



On Saturday 12th June the K.P.A. organised a Tin Rattle and Tombola at Sainsbury's, Walsall. The day was a great success thanks to the generosity of the customers and staff who supported us. Dawn's mum worked very hard again in organising the tombola. We raised £596, a very good result for the day.

Well done and thanks to those who helped and to Sainsbury's.

Party Time in Solihull



Earlier this year Mrs Goulding organised a Charity Dance in aid of the K.P.A. It was held at the Arden Club, Solihull, The event was attended by about 100 people and a supper of roast pork and chips was provided. The DJ. "Mirror Images" donated his services. He had donated a kidney to his daughter. Raffle prizes were also donated by many local traders and businesses. The family helped with the arrangements, ticket printing and posters and also decorating the room for the event. Mrs Goulding raised £800 for the K.P.A. *Again our thanks go to Mrs Goulding for the tremendous support she has given to the K.P.A.*

Patient Transport

Patient transport has been a problem with some patients for some time. I am pleased to report that I am having meetings on a regular basis with the Ambulance Service and management at the Q.E. The sole purpose of these meetings is to find ways to improve the service so that Renal Patients receive the best possible service.

I am pleased to say that everyone recognises that there is a need for improvement and changes are taking place that will see improvements.

I would ask all of you who use Patient Transport and have had problems to drop me a note, or e-mail. If you see an improvement or wish to compliment the service, I would like to hear from you. It is important that the Patients' voices and opinions are heard.

Please let me know.

Nick Flint, Chairman K.P.A.

Visiting arrangements at The New Hospital

Please note the visiting times at the New Hospital have changed:-

2-4pm Next of kin OR one agreed, named visitor
6.30-8.30pm A maximum of 3 visitors per bed.

Woodgate goes to Weston



On a fine and sunny day 52 Patients and carers set off for a day at Weston-super-mare. It was a very enjoyable outing and everyone had a good time.

Even the tide was in when we got there. A first for most of us visiting Weston, reported Dave Davies. It was particularly good as some of the patients find it very difficult to go on outings on their own, but to go with a party of friends and patients and to be supported by staff is very reassuring.

Everyone is looking forward to the next trip which is to see the Blackpool Illuminations.

Woodgate Valley Dialysis Unit.

Peer support for kidney patients

As patients and carers you have far more direct experience of kidney disease than we do as professionals. We appreciate that at certain times, for instance when choosing forms of dialysis or when coping with life after just starting dialysis or having a transplant, there are questions that a patient or carer may have that we are not able to answer. To try and help support patients, I am setting up a formal 'peer support' programme for kidney patients at the QE so that patients and carers can be trained to help support others.

This would involve:

A police CRB check

Attendance at two 2-3 hour training sessions

Occasional contact with well-matched patients to help with their queries.

I would not expect this to be terribly time consuming and expenses would be paid. I would hope to do training sessions during the day and evening if required.

I have several interested transplant patients and am also looking for patients who are currently on dialysis. If you would like more information, please ring Jennifer Davis on 0121 627 2420 or email me on kidneysupport@uhb.nhs.uk.

Clara Day, Consultant Nephrologist.

K.P.A. Presented a Cheque for Research.

The K.P.A. is supporting a 2 year research project at the Queen Elizabeth Hospital.

The Renal Research Department at Queen Elizabeth Hospital has been awarded a donation of £21,000 following fundraising efforts by the Queen Elizabeth Hospital Kidney Patients' Association (K.P.A.).

The KPA, which supports over 2200 renal patients at the Hospital and has been running for 35 years, raised the money through various events such as fun runs and prize draws and donations.

With the substantial donation, the Renal Research Department has been able to fund a new Research Assistant post aimed at providing better resources to enable the research department to be more effective in collecting and distributing data.

Okdeep Kaur is the new Research Assistant employed following our donation. Speaking about the appointment, Dr. Julie Williams said: *"The money raised and donated by the KPA has enabled us to acquire a dedicated pair of hands. Having Okdeep as part of the team will enable us to generate a much larger collection of samples than previously, but importantly it will allow us to collect under high quality conditions. We are very grateful to the KPA for all they have done."*

The cheque was presented by K.P.A. Chairman, Nick Flint, and Treasurer, Mr Len Ingram.



DIARY DATES FOR THE K.P.A.

K.P.A. meetings are held at the Q.E. Hospital on the 2nd Wednesday of each month at 8.00 pm in the seminar room (next to the Boardroom).

EVERYONE IS WELCOME. SUPPORT YOUR K.P.A.

A Concert in aid of the K.P.A.

Performed by

Midlands Chorale

a mixed voice Chamber Choir with members from
all over the West Midlands.

A full and varied evening of musical entertainment
with a hint of Spain

Includes, a concert version of Carmen, South American Advent
music accompanied by guitar drums and keyboard, piano duets
and solo vocal artists

at

St George's Church, Edgbaston, Birmingham.

on the Saturday 27th November at 7.30.

Tickets:- £10 and £8 students and oap's, including refreshments,
available from Pat Bullock 0121 472 6875

All proceeds to K.P.A.

Thanks

We would like to thank the families and friends who have made donations to the Queen Elizabeth Hospital Kidney Patients Association in memory of loved ones.

Our thoughts are with you at this time. Should you wish the money to be used specifically for one of the dialysis units or our K.P.A. Research Fund, this can be arranged.

Please make cheques payable to Q.E.H.K.P.A. and include a note telling us where you would like the money to be used.

Renal Patient View - Know your blood results quicker

Do you have access to the internet? If so you could join 'Renal Patient View'. This is a website provided by the Renal Information Exchange Group, backed by the NHS. The renal department at the QE has linked up to this site to allow renal patients to view their blood results and transplant list status 'on line'. Your latest blood results will be available on the site just a few days after your clinic appointment.

The site is completely secure. You have to give your permission for your information to be listed on the site. You have to be issued with a 'user name' from the renal department and your information can only be viewed using your own specific password.

If you are away on holiday and are taken ill you would be able to share your up to date results with those treating you. The system also has the facility to record your current medications and letters sent from the renal unit to your GP. Although these are not yet available for QE patients.

You can view some sample information at the website www.renalpatientview.org to see if it something you want to do.

If you would like to have access to this facility, please ask when you next attend outpatients. They will give you the form to sign to give your permission for your details to be added to the system. You will then be sent your username so that you can access the information online.

The website also provides useful information for renal patients and a forum where patients can discuss renal issues with other patients.

The K.P.A. would welcome more support from patients or carers

The K.P.A. has supported renal patients and the Hospital for over 35 years and it is hoped that this support can continue for many years to come, but we need more support from patients and/or families to enable us to offer ongoing help.

We meet at the Q.E. Hospital on the 2nd Wednesday of each month. There are over 2200 renal patients treated at the Q.E. and we only have at our meetings on average 15 to 20 people attending. So if anyone thinks they might like to help in any way, please consider contacting any of the committee members or just turn up on the night. You will receive a warm welcome and you won't be pressured into doing anything. Any help will be very much appreciated, especially with the mailings.

We understand that you are all renal patients and it is sometimes difficult to deal with everyday things without volunteering for something else, but we are all renal patients and carers, so we know the problems.

I hope you will think about the K.P.A. and try to come along and meet us.

Look forward to seeing you.

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