



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. October 2008

Visit www.kidneymatters.co.uk

Queen Elizabeth Hospital Kidney Patients' Association

Abe Lincoln visits Burntwood!



On the 4th July Gillian Moore organised an American Disco Night and Pig Roast in Burntwood. It was a great success, and Gillian raised £693 for the K.P.A. which is a fantastic amount.

The pork was extremely popular and a queue was instantly formed with plenty asking for seconds.

Gillian has had lots of requests for a Christmas 'do' so we will have to wait and see. The dancing went on til midnight and everyone said it was a great evening.

Our thanks go to Gillian and all those who supported her. Well done.



Gillian's photo record:

Above: Abe Lincoln and a pink lady (our friends)

Right: Sarah my daughter, as a cowgirl with Superman.

Far right: Myself and Claire, my daughter, as a cheerleader.

K.P.A. Christmas Draw

It's that time again. We have enclosed £5.00 worth of raffle tickets which we hope you will buy or try to sell. There are some great prizes to be won and you will be helping the K.P.A. to support patients and the Hospital. Please make cheques payable to Q.E.H.K.P.A. and return your sold counter foils and the money to Len Ingram. His address is on each ticket.

If you require more tickets please telephone or e-mail any of the committee members who will be only too pleased to send you as many as you require.

Thank you for your support

Visit RENALPATIENTVIEW.ORG

RenalPatientView is a project of RIXG a UK group representing renal patients and the renal team. It aims to provide online information about renal patients' diagnosis, treatment, and their latest test results. Patients can share

this information with anyone they want, and view it from anywhere in the world.

Have a look at this site and see if it would be of interest to you. We would be interested in your thoughts as to whether it would be useful to renal patients.

TVs in R.D.U.

It is with much regret that we have had to remove all the portable TV's from the bedside tables in R.D.U.

These TV's were installed by the Kidney Patients' Association with charitable monies raised by patients and volunteers for the support of renal patients. Time and money has been spent to provide a free service of entertainment, so it is very disappointing that this decision has had to be made.

When the TV's were first put in place, within two weeks controllers and most of the power leads went missing. Batteries were removed and taken from the remote controls. These problems were resolved at a cost to the K.P.A.

It is now very disappointing to see all the TV. cabinets vandalized, controllers taken and power leads also taken. The televisions had to be installed in cabinets to meet health and safety and infection control guidelines. These cabinets have been broken, damaged and vandalized. We will evaluate the cost of repair but think at this stage the cost will be too great to consider replacements.

Should anyone wish to comment on this problem, please contact the K.P.A. on e-mail flintnf@aol.com Please note that the provision of the televisions was by the Kidney Patients Association and not the Queen Elizabeth Hospital and the decision to remove them has been the K.P.A.'s on the grounds of safety.



K.P.A. Tombola and collection at Sainsbury's

Members of the K.P.A. turned out on the 5 July 2008 to raise money.

A tombola organized by Dawn Roach and a collection proved very successful. We raised £450.

The K.P.A. wish to thank the management of Sainsbury's Walsall for their help and support in this and other fundraising activities that we organize.



WWW.KIDNEYMATTERS.CO.UK

Those who have the internet, have a look at our web page. There are some very interesting links and items of interest. We are updating regularly with items that we hope you will find useful. There is also a patients forum which will give you the opportunity to voice your thoughts and ideas with us and with other renal patients. Please post your comments or problems as this may help resolve some of them or pass on ideas as to how to deal with day to day problems of dialysis.

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. Should you wish the money to be used specifically for one of the dialysis units, this can be arranged. Please make cheques payable to Q.E.H.K.P.A. and include a note telling us which unit you would like the money to be used for.

Eating Well on Dialysis

Food is not just about basic sustenance. It is an important part of our culture, celebrations, comfort and general everyday enjoyment. Unfortunately having kidney failure can mean that you may no longer be able to eat and drink exactly what you want, when you want but it is still important to ensure that you have a balanced and pleasurable diet.

Why do I need to be careful with what I eat?

The kidneys remove waste that builds up in the blood. This results from the food and drink that we take each day and from the constant breakdown of our body tissues. These waste products include **potassium, sodium (salt), phosphate and fluid.**

As you are probably aware your dialysis is doing the work of your kidneys in removing these products, as they are no longer able to manage alone. Dialysis itself does not completely replace the work of the kidneys so in order for you to stay fit and healthy it may well be necessary for you to change certain foods and drinks in your diet. This will prevent the excess build up of these waste products and any unpleasant and damaging side effects that can arise from this.

It is important to create a healthy, balanced diet for life.

The key is to think about food in a new way. By understanding what is in the food you eat you can have more control over your well-being.

What is a healthy diet when on dialysis?

Your body needs:

Regular, balanced meals The right number of calories The right amount of protein
A balance of calcium and phosphate levels controlled by diet and medication
More of certain vitamins that are 'washed out' by dialysis

Your body does not need:

Excess potassium Excess salt and fluid

There is no single diet for people with kidney failure and each person has their own individual needs. Some people may need to make very few changes to what they eat and other people may need to make several significant changes to maintain their well-being. This is usually determined by blood biochemistry, severity of kidney failure and other medical conditions. It can sometimes appear that dietary advice is conflicting, confusing and constantly changing but this is often in response to changes in treatment or condition. Remember to discuss any concerns about your advice with your Dietitian or Doctor – they will always be happy to explain!

In order to help you achieve a healthy and enjoyable diet whilst keeping well, try the following points:

Ensure you follow a balanced meal plan and eat regularly

Plan your meals. If you are having a food that is high in a nutrient you have been advised to limit, accompany it with a food that is lower in that nutrient. For example both tomatoes and potatoes are high in potassium so to have bolognese on a jacket potato would be a very high potassium meal. But to have bolognese with pasta (a low potassium food) would be quite suitable.

Take all your medication as prescribed. If you take phosphate binders make sure you know which these tablets are and take them with your food

Know your fluid allowance and try hard to keep to it

Limit salt

Work with your Dietitian to design an eating plan that suits your needs based on your blood results, your current condition and your preferences.

Always ask if you have any questions about your food!

For more information please contact your own Dietitian or the Nutrition and Dietetic Department at the Queen Elizabeth Hospital.

Written by Elaine Turner Renal Dietitian Aston Cross Dialysis Centre

Magazines for Patients

We hope those of you who use the R.D.U. at the Q.E. or the R.A.C. department will have noticed that there are new edition magazines for you to read. The K.P.A has purchased subscriptions to a number of magazines that will be put in the R.D.U. at the hospital and some in the R.A.C. These are for patients to read while they are waiting or receiving treatment. We hope you will appreciate them and if they prove successful, we will look at having some in the satellite units.

If you have any requests for different titles, please let a member of the committee know and we will see if we can add it to our current list of titles.



Paula Mitchell, Senior Nurse, Renal Unit

We were delighted to welcome Paula to our meeting on 18 September. She has recently been appointed to the Renal Unit. Paula previously specialised in cancer treatment and sees her new post as an exciting challenge. She feels that much of her cancer experience can translate into benefits for renal patients. We wish Paula well in her new role and look forward to seeing her again at our meeting on 12 November.
Nick Flint Chairman K.P.A.

Patient transport for haemodialysis

Important. All those who are receiving haemodialysis and using hospital transport should look out for a survey on 15th and 16th October

You will be asked to complete a questionnaire about the service you receive. It will be completely confidential and will ask about the quality of the service and the timing. Please complete it. There will be people around to assist. It is important that the information is obtained which will help improve the service that you all should have.

If you have any comments, make them on the questionnaire.

Patients' Holiday

This year we are going to Crete in October. At the moment we have 12 patients and their partners going, 1 family and 1 single patient. The patients look forward to these holidays as this allows them to try and have some form of normality by being able to go abroad. The number of patients that go dictates how many staff need to accompany them. This year 2 nurses are needed.

Our role out there is to help the patients settle in and take them to and from the dialysis unit for their treatment. We also hold a clinic everyday in our room so that we can deal with any problems that they may be experiencing. We arrange day trips whilst we are there so that they can befriend each other as it is not only QE patients but patients are from all



satellite units ie Aston, Tipton Kings Norton and so on, plus transplant patients.

The nurses only stay for the first week and then the patients stay on for the second week but we put everything in place before we leave so that they do not have to worry themselves. Not only is this a break for the renal patients but we find that this also helps their relatives to have a break as we are there 24/7 for the first week. This gives the relatives time for themselves or even a chance to get things off their mind by talking to the nurses.

The photographs are of patients enjoying the holiday last year. We all hope they have as much fun this year. At least the weather should be dryer and warmer than we have had this summer. We hope all those who go have a very enjoyable time.

Look out next year for the booking forms if you are interested in going along.

The K.P.A. would like to thank Sharon Pilling for organizing the holiday, and sending us this article, and the other members of staff who are supporting her.

Live Donor Meeting

As you may be aware, we have rapidly become the largest live donor transplant unit in the UK. Following on from this we have had feedback from donors who would have wanted certain information after donating. We have taken this on board resulting in our 1st Donor Information Group on 21st July at the Birmingham Council House. A large variety of topics were discussed among a small group of donors with the aim being to work towards producing the required information in written form.

We would like as many donors as possible to have the opportunity to participate in this group. The next meeting will be 3rd November at the Council House

Birmingham at 6.30pm until 8.30pm. If you would like to attend, please write in to let us know so that we arrange a suitable room or if you cannot attend but would like comments to be made on your behalf, again send them in to:-

Donor Information Group,
c/o Sheryl & Sue, Renal Outpatients,
Nuffield House,
University Hospital,
Edgbaston, Birmingham, B15 2TH
Sheryl Parsons Renal Transplant Co-ordinator

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.

CONTACT YOUR K.P.A.

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