



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. February 2008
www.kidneymatters.co.uk

Queen Elizabeth Hospital Kidney Patients' Association

Annual Christmas Draw

The Christmas Draw was a very great success. We sold over £3000 worth of tickets. We would like to thank all those who supported us and to those who gave us a donation. The Draw took place at our January meeting and renal Nurse Jane Wallace drew the winning tickets. Congratulations to the lucky winners. There is a full list of winning numbers and prize details on the back page and also on our Web site.

Thank you for supporting the K.P.A.



Sainsbury's Support the K.P.A.

The K.P.A. thank Walsall Sainsbury's for allowing us to sell tickets and collect for the K.P.A.. It was a very cold and windy day for those who came out and supported this very worthwhile event. Thanks to all involved.

If any patient or carer would like to join us at future fundraising events please contact any of the committee. Contact details are on the back page.



Disco a swinging success



Gillian Moore from Burntwood contacted the K.P.A. and asked if she could organise a disco at a local school to raise money for the K.P.A.. This she did and raised £689 for the funds.

It was the first time she had organised such an event and she was very pleased with the support from friends and family.

Gillian enjoyed the event so much she said she would organise another later this year—watch this space.

This is Gillian presenting the cheque to the K.P.A. and receiving a certificate of thanks.

WWW.kidneymatters.co.uk We now have a web page. You can exchange information and find out about the K.P.A.; tell others about holidays; ask others for help and advice. Have a look at it and let us know what you think.

The K.P.A. would like to thank Tony Wright from Telford, who has set up and is helping to run the web site for us.

Eating Out

Everyone enjoys a meal out or a take-away, be it for a special or romantic occasion or just because you don't want to get the pots and pans out one night. But if you're on a renal diet can you still enjoy a meal out? The answer is, of course, yes but a little planning and being a little careful with what you choose can make all the difference and help you have an enjoyable and healthy time.

Here's your guide to eating out on a renal diet:

- If you are limiting your fluids intake, take less during the day if you wish to drink more with your meal
- Spicy and salty foods are likely to make you thirsty and encourage you to drink more. Many Chinese dishes, in particular, contain monosodium glutamate which may make you very thirsty so cut down on fluid before your meal.
- Cut down on high potassium foods earlier in the day to allow yourself more choice at the restaurant or take-away
- Try to balance the potassium content of your meal. For example, if having chips, which are high in potassium, avoid having mushrooms or tomatoes with them. If having a tomato rich meal, such as bolognese, choose pasta or rice with it, rather than potatoes.
- Mostly try to choose the lower potassium rice, pasta, garlic bread, naan bread rather than chips and jacket potatoes.
- It is safer to indulge in phosphate rich foods rather than those high in potassium so some pate for starter or some cheese and biscuits at the end of a meal might be better treat than a chocolate and nut gateaux!
- **Remember- you will still need to take your phosphate binders with your meal so make sure you take them with you!**

Here are a few food ideas to help you decide what to choose when eating out:

Pub Grub

- Most grilled, roast or fried meat, poultry and fish will be suitable as will roast dinners with boiled or mashed potatoes, Yorkshire pudding and veg with mint or apple sauce. If you need to be careful with your potassium and are choosing roast potatoes, keep it to a small portion as they may not have been pre-boiled.
- Avoid soup as a starter as this can be high in both salt and potassium and will need to be included as part of your fluid allowance.
- Prawn cocktail, melon and pate make suitable starters.

Indian Meals

- Try to avoid very spicy dishes, as these are likely to make you thirsty. Biryani are drier curries and may be useful in avoiding excess fluid.
- Choose balti, rogan josh, bhuna with rice, naan bread or chapattis and try to choose plain breads rather than Peshwari or Keema which are higher in potassium and salt.
- Avoid Korma as this is often made with coconut milk, **which is high in potassium.**

Chinese

- Meat and poultry dishes such as sweet and sour, in lemon sauce and chow mein would be suitable. Eat with rice or noodles.

Italian

- Pasta is low in potassium and phosphate and a great choice. Enjoy with carbonara, bolognese or other sauces. Try to avoid those with both tomatoes and mushrooms.
- Pizza is suitable but again try to avoid mushrooms as a topping. Choose meat, poultry, onion, sweetcorn, pineapple for example instead.
- Garlic bread makes a great accompaniment.

Desserts

- Ice-cream, gateaux, meringue, cheesecake, apple pie or crumble are all suitable but try to avoid desserts containing chocolate, coffee, dried fruit or nuts if you are watching your potassium intake.

You may wish to have a tippie with your meal. Spirits tend to be lower in potassium than wine and beer and you could try them with mixers such as lemonade, soda water, ginger beer or lime cordial. Avoid fruit juices due to their high potassium

Content.

If choosing beer, limit your intake to half a pint to avoid excess fluid and potassium and if you prefer a glass of wine with your meal white wine tends to be a little lower in potassium than red wine. *But remember, all drinks need to be counted as part of your fluid allowance if you have one.*

For more information on eating out please contact your Dietitian or call the Nutrition and Dietetic Department at the Queen Elizabeth Hospital on 0121 627 2310.

Bon Appetit!!

Information

We are always being asked for information and suggestions about holidays on dialysis, either C.A.P.D. or haemo., particularly from patients new to treatment. So if you could send any details about your experiences, good or bad, or if you have come across a travel company which has been particularly helpful, we can pass this on to others through Kidney Matters. Your help would help us to help others.

Kidney Research UK's flagship awareness and research programme,

ABLE and other work and projects by Neerja Jain, RGN, BSc (Hons), MSc ABLE Development Manager, Kidney Research UK.

ABLE – A Better Life through Education and empowerment

Over 3 million people are affected by Chronic Kidney Disease (CKD). Kidney Research UK, the leading national charity dedicated to research that will lead to better treatment and cures for kidney disease has developed the ABLE programme which seeks to research and raise awareness of the issues among “at risk” groups. Initially the programme focussed on the Black and Minority Ethnic (BME) communities who are up to five times more likely to get kidney failure than White Caucasians. Recently the scope of the programme was broadened to encompass all those at risk and the useful lessons learned from the seven initial projects are being used to inform the future of ABLE and other CKD projects

The Leicester ABLE project has learnt from the South Asian community about the dearth of appropriate information on kidney disease – and importantly, what resources to provide that will be of benefit. A real concern was that there was very little knowledge about CKD even among those most at risk, such as those with diabetes (a South Asian person with diabetes is TEN times more likely to develop kidney failure compared to a white European person with diabetes!). So, the team, led by Professor John Feehally and comprised of patients and community members, developed innovative resources that were well received by all stakeholders. These included an interactive DVD in English and five South Asian languages - copies are available from our Kidney Health Information Line (KHI) on 0845 300 1499. Clips can be seen on our website: www.kidneyresearchuk.org/able.

The charity has also led on the **Patient DVD Project**. Aimed at informing patients about living with CKD, it was developed in partnership with British Renal Society (BRS) and working with other leading groups including the National Kidney Federation (NKF). The content was driven by patients. There are separate DVDs, one for CKD and one for living with kidney failure. These can be obtained from our KHI (Kidney Health Information line 01733 704650).

Research work that has been completed over the last year has shown...

- A potential way to increase iron in the body to prevent anaemia
- How to improve outcome, relapse and survival in patients with vasculitis
- Identified a new molecule present in rejecting kidney transplants
- Blocking a hormone can inhibit the growth of cancer cells
- How to promote repair to kidney cells

The charity's Patient Grants Scheme

Each year we award support grants to patients affected by kidney disease who receive dialysis treatment or live with a transplant. Last year we spent nearly £120,000 on patient welfare, which included £70,000 of direct grants awards. See Information section on the website: www.kidneyresearchuk.org
For more information on Patient Grants – call 01733 704658/75

Thanks

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

We have received donations in memory of Mrs Marie Hensman, Mr Eric Fletcher and Mrs Gwen Kingston. Our thoughts are with the families and thank you for supporting the K.P.A..

We would also like to thank all those who have chosen to support the Queen Elizabeth Hospital Kidney Patients Association with donations to mark a special occasion.

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.

Following this educational programme, we are delighted to report from our research focus groups that people were informing us that, as well as an increase in knowledge about CKD, some also reported making pivotal lifestyle changes in order to reduce their risk of diabetes and hypertension (the main causes of kidney failure in these communities).

The West London ABLE project led by Dr Liz Lightstone and colleagues, has demonstrated that kidney disease in Indian Asian and African Caribbean men may deteriorate more rapidly to Established Renal Failure. Long term, the study aims to identify the reasons for this faster deterioration so Kidney Research UK has recently funded this follow on work.

The Birmingham African Caribbean ABLE project led by Dr Adu, Dr Rayner and Sister Pat Simoyi, has produced some innovative literature aimed at this community and the relatives of renal patients who are at greater risk of CKD. A group of six Peer Educators have also been trained and are helping to deliver the key messages at community grass roots level. *We are, however, in need of further funding in order to continue this project beyond June 2008!*

The other ongoing ABLE projects include one on organ donation and examining attitudes so as to inform future public policy, based in West London and led by Dr Anthony Warrens. Another, on exploring the pathway of the patient with diabetes and how we can improve education, screening and monitoring for this most vulnerable “at risk” group. Patients may then be prevented from reaching the need for dialysis, or at least are better prepared for it.

4th FLOOR REFURBISHMENT and RDU ALTERATIONS

- Between January and March there will be some building and refurbishment work occurring in the E4 ward areas.
- The aim of this work is to enable more inpatient dialysis treatment to occur by the bedside. This will limit the movement of patients from one area to another and help improve infection control.
- This work will mean some disruption to patients and we would like to apologise for any inconvenience that may occur during this time.
- There will be a need to move some patients whilst work is carried out in the individual areas, however we will aim to keep the majority of our patients within the 4th floor area where possible.
- Medical teams will always be on hand to see patients wherever in the hospital they may be and this will continue to be the case.
- Additionally there has been some work carried out on widening the door into the main hospital from RDU.
- This is to allow us to take more bed bound patients into RDU and therefore improve the patient journey for those patients who are currently coming in on stretchers.
- The change will ensure that North 4 Dialysis is used as intended, which is as an acute (inpatient) dialysis area, and for RDU to be fully utilised as a chronic (outpatient) dialysis facility.
- As RDU is on the ground floor this will mean that patients who are bed-bound will not have a long wait for lifts to arrive and take them up to the dialysis area and this we hope will reduce some of the stress of having to come into dialysis.

Should you have any issues during this time, please feel free to speak to myself
Emma Skinner Senior Nurse {Matron}

Tribute to a special member of the K.P.A.

It is with much sadness that on 4th November Marie Hensman passed away after a short illness. Marie was a very active member of the K.P.A., always at our meetings and always enjoying being involved. Marie will be very sadly missed by us all and everyone who met her. Our thoughts are with Clive and the other members of her family at this very sad time.

It is with much sadness that we have to share the news that Mrs Ann Fletcher recently passed away on the 14th December. She was a long-standing member of the K.P.A. and our thoughts are with her family at this sad time.

Christmas Draw - The Lucky Winners

Name	Ticket No	Prize	Name	Ticket No	Prize
MR F KANJI	24544	£300.00	M F KANJI	24558	£5.00
MR A HAYFIELD	04300	£150.00	MISS A TIMMINS	02118	£5.00
DAY CENTRE	15205	£75.00	MR KIMBERLEY	21241	£5.00
MR S WILLIAMS	04351	£5.00	MR R SMITH	33326	£5.00
MR D SMITH	06763	£5.00	MISS O' TOOLE	01266	BOOK
MS S MELIA	34451	£5.00	MR S McPHEE	37403	BOOK
MRS J COSNETT	21004	£5.00	MR STIRCHLEY	39590	BOOK
LEAH GEES	37618	£5.00	MS J BIRCH	37437	BOOK
MR T BULL	01380	£5.00	MR AINGE	33092	BOOK

All prize winners have been conetacted. Thanks for your support.

CONTACT YOUR K.P.A.

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