



KIDNEY MATTERS

The Newsletter of the Q.E.H.K.P.A. JUNE 2007

Queen Elizabeth Hospital Kidney Patients' Association

Faye and Natasha supporting the C.A.P.D. Unit.



Faye Cheesman and her friend Natasha Cohen On the 1st April, Tasha and Faye set off from the Thames Barrier in Woolwich



Eleven days, 1 minor sunburn, various assorted blisters, 3 inflamed tendons, 1 pack of Ibuprofen, 44 gallons of water (what we drank, not the Thames itself!), enough snacks to last about a month, 40 minutes of light rain, approximately 132 hours of almost unbroken sunshine (we really were so lucky with the weather), 2 bottles of sunscreen, 1 minor disagreement over the map, a host of fantastic people (both known and unknown to us) without whom the walk just wouldn't have been possible, an awful lot of sheep (Tasha narrowly avoided having to deliver a lamb, Faye helped to pull one out of the river!), at least 5 counties and some of the most beautiful countryside later we arrived at the source stone near Cirencester. Unfortunately, there was no water right at the source, but we were just so pleased to see it that we barely noticed!

We walked through (amongst others) Woolwich, Greenwich, Westminster, Battersea, Wandsworth, Chelsea, Putney, Fulham, Barnes, Hammersmith, Chiswick, Kew, Richmond, Twickenham, Teddington, Kingston, Hampton, Sunbury, Shepperton, Chertsey, Staines, Windsor, Eton, Bray, Maidenhead, Cookham, Bourne End, Marlow, Henley, Shiplake, Sonning, Reading, Whitchurch, Goring, Wallingford, Abingdon, Oxford, Eynsham, Lechlade, Cricklade and Ashton Keynes on our way from A to B (and we learned that the nicest houses in any area can be found by the river!).

Ultimately, we had the most fantastic time and it was just amazing to see the river change day by day from the working river of the Isle of Dogs to the iconic river under Tower Bridge; the rather genteel river of Kew and Richmond, through to the little meandering tree-shaded river of the Cotswolds.

Enormous thanks are due to all those who agreed to sponsor us – it was thoughts of all of you that spurred us on when things got hard! We're still in the process of collecting together the money and are looking forward to being able to send out news of a final total.

The support of the staff in the CAPD unit at the QE Hospital was really important to Faye's mum when she started on CAPD and we're raising money to support their programme of pre-treatment counselling, information and advice
Tasha and Faye x

Mission accomplished!

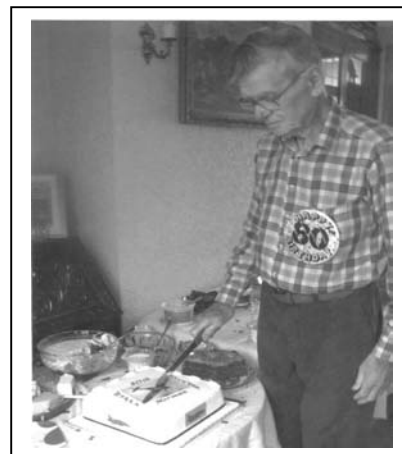
To date about £2000 has been raised. The thanks of the K.P.A. and the Q.E. go to Faye and Nasha for a tremendous fund raising event.

Thank you for supporting the K.P.A

Flying high at 80

Norman, a renal dialysis patient at the Q.E. and a very active and loyal supporter of the K.P.A. celebrated his 80th birthday recently and to mark this occasion his family are treating him to a once in a life time flying experience, Later this year he will be taking the controls of a vintage Tiger Moth Bi-plane and fly around the Midlands. We all wish him Many Happy Returns of his birthday.

We hope to have a photo of him at the controls in the next Magazine.



Polycystic Kidney Disease Charity

The Polycystic Kidney Disease Charity, established in 2000, is the only UK charity to focus on the needs of adults and children with Polycystic Kidney Disease (PKD).

PKD is the world's most common, life-threatening genetic disease, affecting an estimated 12.5 million people worldwide, around 60,000 in the UK, irrespective of gender or race. It is the 4th cause of renal failure and incurable.

The PKD Charity aims:

- 1 To provide information, advice and support to those affected by PKD. Patients often receive limited or confusing help once diagnosed. The Charity offers e-mail and phone support, has just started support groups, runs a popular web forum, organises an annual mini-conference and publishes information booklets and newsletter.
- 2 To fund research into determining the causes of PKD, discovering treatments and a cure The Charity is building its own research fund.
- 3 To raise awareness of PKD, providing information about PKD to patients, the public, the medical community and the media.

For more information visit the Charity's website www.pkdcharity.org.uk
or call Tess Harris, Chairman, on 020 7387 0543.

**The PKD is organising an Information Weekend Friday on July 6 to Sunday 8 July 2007 at the Queen Elizabeth Postgraduate Centre, Queen Elizabeth Hospital, Birmingham
To attend this event please contact Tess Harris on 020 7387 0543**

Fundraising WE NEED YOUR SUPPORT.

The K.P.A. is organising a "Lock Winding Day" on the canal side at Kings Street Locks Birmingham. The event is to raise money for the K.P.A. and to promote Renal Awareness. It is on Saturday September 1st 2007 from 9.00 am till 4.30 pm, if you would like to support the K.P.A. please come along and help either with the Lock Winding or manning the stall. Please contact any of the committee for further details.

We have various fundraising events during the year. If you would like to help please contact our secretary who will be pleased to give you details.

TVs in the RDU at the Q.E

The K.P.A. have installed 6 televisions in the RDU at the Q.E. and in the next few weeks hope to have the remaining 8 sets installed. This will be one TV for each patient on dialysis. We hope the patients enjoy using the sets as they have cost nearly £2000 and a lot of hard work for members of the K.P.A. to organise them. Happy viewing.

Letters to the Editor

If you would like to add your comments, ideas or share your experiences with others, please send them in to us and we will include them in the next edition of the Kidney Matters

Donations

The K.P.A. would like to thank all those who have made donations to our funds. Where possible, all are personally acknowledged. Anyone who would like to support the K.P.A. please contact us for help and guidance. You may wish to make a donation, organise a coffee morning or run a marathon, Please make cheques payable to Q.E.H.K.P.A. and send them to our Treasurer.

Living Donations

Anyone considering living donation who would like to talk to other patients who have experienced the procedure can contact our support group on 07834 324756.

The Big Birmingham Donor Day

Monday April 30th saw the first “Big Birmingham Donor Day” in Victoria Square. Representatives from many organisations came together to promote “donations” in all forms. There was BODY, The National Blood Services, U.K. Transplant, Kidney Research UK, The Anthony Nolan Trust, Transplant Sport UK, Heartlands K.P.A., Queen Elizabeth Hospital Kidney Patients Association The Living Donor Support Group and The Queen Elizabeth Hospital.



The purpose of the day was not just to encourage people to sign the organ donor register, but to also raise awareness of the need for more blood and bone marrow donors, as well as highlighting the possibilities of living donation. We are extremely grateful to QE staff for lending their support, including Dr Ball, Dr Cockwell, Elizabeth Armstrong and some of her donor co-ordinator colleagues and Sue Moore who helped with displays and literature.



The day was organised by Pat Hall of BODY and The National Blood Service, and hosted by the Lord Mayor of Birmingham, Cllr Mike Sharpe, himself a renal patient. This was the first time all organisations had worked together to highlight the shortage of all forms of donors. Everyone involved greatly appreciated Jasper Carrot giving up his time to come along and support us

Lord and Lady Mayoress,
Pat Hall from BODY, Jasper Carrot, and
Arnold Brookes, our Master of Ceremonies

Renal issues were a large feature of the day with patients from Heartlands KPA and Queen Elizabeth Hospital Kidney Patients Association on hand to talk to people about kidney disease, forms of dialysis and transplantation, including living donor kidney transplants. It was a great opportunity for us to work together with Carol Sidaway and Nad Hussain from Heartlands towards the same goal. Neerja Jain from Kidney Research UK provided information about prevention, treatment and management of kidney diseases.

As well as the main event in the Square, there were displays in Selfridges, BHS and M & S (manned by Len & Joan Ingram from our KPA).



Members of the Birmingham Transplant Games team ably demonstrated the positive effects of transplantation as they performed a relay to present a commemorative baton to the Mayor.

Christine Evans, Chairman of Transplant Sport UK questioned why this was the first event of its kind and hoped that it wouldn't be the last.



With 1700 blood donors needed each week in Birmingham alone, and over 7000 people on the transplant waiting list, the need for events like this is clear.

Everyone agreed the day was extremely worthwhile and generated a lot of interest, but it's success cannot be measured in numbers. We talked to many people and hope that they took our message of “Donation” home with them to their family and friends to generate further discussion and hopefully action.



Dawn & David Roach from Queen Elizabeth Hospital Kidney Patients Association, whose display provided information on living donation, with Jasper and Dr Paul Cockwell.

BBQ RECIPES FOR FOLKS ON A RENAL DIET

As a renal patient, you may feel that you cannot enjoy your food and often do not know what you can and can not have. As the summer season is upon us we have put a few recipes together that we hope will give you some ideas for barbeques. If you like to have a "no fuss" barbeque you can always buy the usual sausages, beef burgers, chicken portions or lamb/pork chops. If you want to be a bit more adventurous please contact your dietitian who will give you a copy of the recipe book but we have included a couple of recipes below for you to get started with.

As the potassium content of the dishes may be higher than usual we recommend you avoid potatoes and have rice, pasta, bread (such as pita bread, French stick, tortillas, ciabatta) instead.

Your intake of salt can also be increased at barbeques due to sauces, dressings and any additional salt added to the food, this will make you thirsty and will increase the chance of drinking too much. If it is your barbeque - ensure you do not add salt to things like rice and pasta and make sure you do not add any to your food. If you are the guest then avoid adding salt to your food and limit the sauces you have.

Remember your phosphate binders, as your intake of meat/fish/chicken tends to be higher at barbeques.

Be careful of your fluid intake, take sips to make it last, use ice cubes, avoid excess salt.

Glazed Lamb Chops

4 Lamb chops
50g butter or margarine
2tbsps honey
2 tsp wholegrain mustard
Pepper

Method:

Beat the butter/margarine until pale and creamy
Beat in the honey, mustard and pepper to form a paste
Brush this mixture over the chops, and place in fridge for about 1 hour
Place on the BBQ until cooked throughout

Fish Kebabs

Serves 3
1 lb firm white fish
1/2 tsp salt
1/2 cup plain yoghurt
6 cloves garlic, peeled

1 fresh ginger root, peeled, cut into 1-inch pieces
1 tablespoon garam masala
1 tsp ground coriander
1 teaspoon cayenne pepper
1 lemon, cut into wedges
2 hot green chilli peppers, seeded

Method: Cut the fish into 1-1/2 inch cubes. Put about five pieces on each skewer and sprinkle with a little salt. Make a paste from the yoghurt, garlic, ginger, garam masala, coriander and cayenne pepper. Spread mixture on fish and refrigerator 2 hours. Remove from refrigerator and grill 10 minutes or until fish flakes easily with a fork. The skewers can be sprinkled with a little oil during cooking, if required. Garnish with the lemon and fine rings of green chilli pepper.

If you have any favourite barbeque recipes you think other renal patients would enjoy, please let your dietitian know and we can include it in future copies of the recipe book.

Service of Thanksgiving and Remembrance

The Donor Family Network are organising a service of thanksgiving and remembrance which is non-denominational and an opportunity to reflect on the miracle of life This is a lovely service for all who have been touched by transplantation - liver, kidney, heart or any kind of transplant. Recipients, donor families and friends are all welcome.

Sunday 8th July 2007 at 2pm
at St Margaret's Church, Chapel Lane,
Great Barr, Birmingham

There will be refreshments following the service at the nearby Memorial Hall.

CONTACT YOUR K.P.A.

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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.