



HHKPA NEWS

FROM THE CHAIR

I thank all the members who attended the AGM in November and voted for me as Chair for the forthcoming year. I would like to thank Eileen Parker, who had held the position for four years, and express my pleasure at knowing her knowledge and expertise will not be lost, as she has become Secretary.

I will try to carry out my responsibilities in this important role to the best of my ability but I will need your support and that of all the committee members.

This is the first Newsletter of 2002 and we welcome a new Editor, Nimrit Foody. She has taken on this position from Susan Frade who I would like to thank for all her hard work.

I look forward to working with you all.

Don Taylor

FROM YOUR EDITOR

Welcome to my first newsletter. I hope you find it interesting and informative. We are looking to publish three Newsletters a year but to do so we require articles from members of the KPA. I hope some of you will take on the challenge and write an article or letter for publication. Even if you don't want to write an article, but have an idea for a topic you would like to see discussed then we will try our best to get it written.

I look forward to your suggestions and feedback on the newsletter.

Nimrit Foody

THANK YOU JOHN

KPA member John Barton died suddenly in November 2001. He had been a loyal KPA committee member for many years. In that time he made a significant and beneficial contribution to the debate and development of the Association.

We are all thankful for the voluntary work he undertook for the benefit of all of us. We also give our grateful thanks to his family and friends for the collection made in his memory. This has been given to the KPA to be used for the benefit of other kidney patients.

LOOK OUT FOR...

KPA BROCHURE



For some time a new KPA brochure, explaining who we are and what we do, has been needed. At last, with the considerable help of former Newsletter Editor Susan Frade and designer Sujata Aurora, we now have one. It gives some basic facts about kidney failure and transplantation together with information about the KPA and examples of the work we do for the benefit of our members. Suggestions on how you can help the KPA, and benefit others with kidney failure, are also included. The brochure also gives an opportunity to make a financial donation to the Association. Two copies are enclosed with this Newsletter, one for you to keep for future reference and the other, we ask you to pass on to a friend or business who would consider giving a donation. This would mean more than six hundred brochures being distributed to potential donors. If you would like any more brochures, then please contact Nimrit (contact details on page 4).

DONOR CARD



One of the roles of the KPA is to "Promote the NHS Organ Donor Register and Donor Card." To fulfil this aim, two copies of the Organ Donor leaflet and card are included with this Newsletter. As we all have kidney failure and many of us are waiting for the call to indicate there is "A kidney for you", you are asked to give these to relatives or friends who might become potential organ donors and help save lives.

**Please do pass them on
Thank you**



IT'S HOLIDAY TIME!



Holiday Advice for Kidney Patients

If you are intending to go on holiday either abroad or within the UK here are some guidelines. Please note that the processing of any patients' request is based on individual circumstances. You must never pay for accommodation, travel expenses or any other costs before you have spoken to your consultant and they have given you permission to travel. The Hammersmith Hospital Trust will not reimburse any expenses and it will be up to you to pay for these.

General Points

You must take out Travel Insurance! It is very costly to have any medical treatment abroad and the money cannot be recovered from the NHS. A list of insurance companies that cover dialysis and transplant patients can be obtained from the Transplant Nurses or Bev Nicol, the Renal Dialysis Co-ordinator (0208 383 8149 Fax: 0208 383 8543). On the form you must declare you are a Dialysis or Transplant patient as failure to do this will invalidate your insurance. In addition, if you are travelling within the EEC you should take form E111 - available from the Post Office. Your unit can also supply a letter to take with you, which includes your latest results, a list of your tablets and any other pertinent information.

It is obviously sensible to take heed of any health issues when abroad, i.e. boiling drinking water or only drinking from bottles with sealed caps. Even though you may have originally come from the country you are visiting, it does not mean you will have the same immunities you once enjoyed.

Make sure you take more than enough tablets to cover any delays as they are expensive to replace and you must continue taking them.

Haemodialysis Patients' Holidays

These are more difficult to arrange and the more notice you can give the better! A minimum time of two months is necessary. Contact Bev before you arrange your holiday. The NHS can only pay for dialysis within limited areas.

Peritoneal Dialysis Patients' Holidays

Inform the nurses in PD in sufficient time of your holiday intentions, so that the consultant in charge of your overall care can give you a clean bill of health to travel. No holiday PD bags will be

organised until this has been approved.

Once that has been agreed then contact Bev. An average of two months is required to organise the delivery of your bags. This will depend on the destination and the availability of the bags, as they may need to be delivered from some distance, overland or by sea. Extra time will be needed if the country you are visiting does not use the same PD system as you. If you are on APD Bev will need to check if this is possible in the area you are visiting (i.e. electrical supply).

When you contact Bev, have all the details of your holiday ready. She will need your travel dates, and the delivery address, contact name and phone number of where you are staying.

The bags will be delivered a few days before you arrive, so you must ensure you have permission for them to be stored in a dry and safe place, and that someone will be there to receive the delivery. A detailed letter will be sent to you from the Baxter Travel club prior to your trip, describing what will be delivered. You must read this letter and make sure that you are fully aware of its contents and confirm that there is a sufficient number of bags for your stay. The letter also includes information such as the closest CAPD unit. If there are any problems then you must contact Bev immediately. Remember to take this letter with you on holiday.

Please note that you will need to take your own ancillaries (caps, shields etc.). Please ensure you have notified Unicare in advance so that extra items can be delivered one month prior to your departure in your usual monthly delivery. As some countries may deliver minicaps but no shields, please check with Bev to see what needs to be taken.

Transplant Patients' Holidays

It is not recommended that transplant patients travel abroad in the first six months following a transplant, as there are so many potential problems. After six months please check with your Doctor at a clinic visit if you are fit to travel abroad. Please do not make any arrangements before checking with your doctor as this may result in you losing any money you have spent if you cannot travel.

Some destinations may require you to have inoculations before you visit. Please think about this in good time. Your own GP should be able to give you the correct inoculations or you can go to a Travel Clinic. Please ensure that your GP or the clinic are aware that you are a transplant patient and are only allowed "killed vaccines" (i.e. no "live" vaccines, such as polio). The Transplant Clinic can advise you, but cannot give any inoculations.

Remember to use at least factor 40 sunscreen and cover up as much as possible. Skin cancer can be very serious for transplant patients, because of the drugs they take. These make them more prone to skin cancers than the general population.



Don't Forget To...

- ◆ Obtain Doctor's approval before you book
- ◆ Take out Travel Insurance
- ◆ Take enough medication
- ◆ Carry your medication in more than one bag
- ◆ Take the number of the nearest hospital/CAPD unit

Never pay for your holiday before you have spoken to your consultant and have permission to travel. The Hammersmith Hospital Trust will not reimburse any expenses!



TRANSPLANT ACHIEVER

The Eileen Quinn-Smith Story by Don G Taylor

Eileen Quinn-Smith who is a kidney patient and member of HHKPA recently became Sports Personality of the Year for Bedfordshire. The award was made following her outstanding performances in the British and World Transplant Games.

In 1986 when already a promising athlete she was struck down with a virus which severely damaged her kidneys, paralysing her so she was unable to walk. At this time her mother came to the rescue and agreed to donate one of her kidneys to give Eileen a chance of recovery.

Soon after the operation at Hammersmith Hospital Eileen went to live abroad but returned in 1995 and resurrected her athletics career. From the start Eileen found success in the sprints and jumps. To date she has won eleven world and thirty national transplant medals.

Last year was particularly successful for her, winning both the 100 metres and 200 metres at the British Transplant Games held in Leeds. She also won Bronze medals in the 400 metres and Long Jump.

She then joined the British Team for the World Transplant Games in Japan. Early in the championships she took Bronze medals in the long and high jumps. Then came the relay in which she ran the second leg. The athlete to whom she was handing the baton went too early. Eileen, realising the error, accelerated and whilst at full stretch just managed to pass the baton allowing the British team to gain a dramatic victory. The other team members were oblivious to the fact that Eileen, in her determination to pass the baton, was left spread-eagled on the track unconscious. She also suffered a badly bruised and lacerated left side – luckily this was not the side with her transplanted kidney.

Looking back Eileen reminisces, “I came round and there were all these track officials and physios

standing over me. Even though I was in considerable pain I laughed at the twenty-five Japanese medics running across the track to my aid.”

Eileen’s effort was judged the most heroic performance of the Championships. She regrets her injury prevented her competing in two further events, where with good form she was optimistic of winning more medals.

Eileen is now a media personality and is often interviewed for radio, television and the newspapers. In her working life Eileen is a Recruitment Officer for British Airways and travels the world as a steward. She is fond of animals, is a volunteer at an animal sanctuary, has two dogs and five cats of her own, and is also studying for a Law degree.

Eileen is a member of Bedford Athletic Club and was ecstatic when she was named as Bedford’s Sports Personality of the year. In previous years the award has been given to Olympic Gold Medallist Rower Tim Foster and World Cross Country, Half Marathon and London Marathon Champion Paula Radcliffe. Eileen expressed considerable pleasure and satisfaction at winning this prestigious award following such high profile sports personalities.



In the future, Eileen intends to continue her athletics career, not only competing in events for people with transplanted organs but in open athletics too.

The Hammersmith Team expect their star performer to achieve more successes this year in the British Transplant Games in Loughborough in August.

There can be no doubt that Eileen Quinn-Smith has used her rejuvenated life, following her transplant, to be active in many ways. She is thankful for the support and advice she has been given by the Consultants, Doctors and Nurses at Hammersmith Hospital Renal Unit. If a role model is needed for anyone with a transplanted organ Eileen is outstanding.

SUPPORT THE BRITISH TRANSPLANT GAMES
To be held at Loughborough over four days commencing 29th August. For more information contact Don Taylor (contact details on page 4).



HHKPA ANNUAL GENERAL MEETING 2001

By Eileen Parker

The HHKPA Annual General Meeting was held on 20th November 2001 and was well attended. Thanks, we are sure, to the excellent refreshments provided by our President, Gordon Williams. We would also like to thank Dr Clutterbuck and Dr Warren for their highly informative presentations on the subject of 'Drugs, Dialysis and Donors'.

The Chairperson, Eileen Parker, reported on the success of the association in generating revenue for the benefit of members, as well as organising social events and producing newsletters. In total, general donations for the year amounted to nearly £4,500, while total fund-raising generated almost £5,500. This included a profit of over £1,000 from July 2000's sponsored walk and £2,287 from December 2000's grand draw. With bank interest added, total income was almost £10,400. Over £6,000 was spent on the purchase of hospital equipment. The main items purchased were two electrically controlled beds and a blood pressure monitor. In addition £1,250 was

spent on patients' welfare payments.

There was also a report on the development of Hammersmith Hospital as the West London centre for specialist renal services. This should bring about a great improvement in patient care and provide modernised facilities. Eileen emphasized the importance of the HHKPA in playing a key role in the forthcoming changes to ensure that the best interests of the members are promoted.

Thanks were given for the valuable work undertaken by our former Secretary, Dave Songest, and to Susan Frade, the former editor of our newsletter. Members were also reminded of the support and work undertaken on our behalf by the late John Barton, who had been a committee member for many years and who sadly died last year.

We plan to hold our next AGM in October or November 2002 so watch this space to find out details of who our guest speakers will be. We hope to see to you there.

NEW NAME FOR THE NEWSLETTER!

We are looking for a new name for the newsletter. So get your thinking caps on and send your suggestions to the editor by 1st August 2002. The winning idea wins a copy of *Food for Life (A recipe book for the Dialysis patient and their family)* by Lawrence Keogh.

THANK YOU FRESENIUS MEDICAL CARE

On 21st February, Don Taylor represented the KPA at a special function arranged by Acting Lead Nurse Davina Gilbert. This was to celebrate the sale of one million dialysers in the UK by Fresenius Medical Care. In recognition of this first time achievement Don received a cheque for £1000 for the KPA to use for the personal care of patients.

Hammersmith KPA thanks Fresenius for their generosity and for choosing us as the beneficiary. A further £1000 was presented to Davina Gilbert for the Renal Education Fund.

NEW MEMBERS NEEDED

All six hundred renal patients of Hammersmith Hospital and the satellite units at Ealing, West Middlesex and Ashford are automatically members of the Kidney Patients Association (KPA).



The affairs of the KPA are managed by a voluntary committee comprising patients, consultants, doctors and nurses. Our main function is to raise funds to provide services and equipment that will benefit all of you beyond what can be provided by the NHS.

We urgently need six new members to join the committee and hope some of you will be interested in offering your services in this way. We meet about six times a year on a weekday evening at the hospital between 6-30pm and 8-30pm. Anyone interested in joining the committee or wanting more information can contact Don Taylor. He is waiting for your call!

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