



HAMMERSMITH KIDNEY NEWS

Newsletter of Hammersmith Hospital Kidney Patients' Association Registered Charity 275771

February 2004

ANNUAL GENERAL MEETING 2003 By Eileen Parker

In his annual report at our AGM on 23rd November 2003, our Chairperson, Don Taylor focused on the main aims of our association. In addition to improving patient facilities and quality of life these include providing support and information for patients and their families, supporting national renal organisations such as the National Kidney Federation and raising public awareness of kidney disease and renal issues.

Whilst we were not quite as successful with fundraising as in the previous year we still raised over £12,000 in 2002/3 in many diverse and innovative ways. In addition to acknowledging the generosity of the companies which had contributed to our funds Don particularly thanked all the members, friends and relatives who had organised their own events and sponsorship for our benefit. Sadly, as last year, a large number of donations were received in memory of patients who had died and Don thanked their families for their generosity. The sale of our Christmas cards once again went very well.

In 2002/3 over £13,500 was spent on items and services for patients, which included: two electric beds; numerous televisions for wards, clinics and satellite units; an ice-making machine for the dialysis unit; welfare payments; refurbishment of the Ealing satellite unit; grants for members attending the fete at Emsworth and the National Kidney Federation conference; seasonal refreshments and the Christmas party. There was also support for the costs of a pre-dialysis seminar, our website www.hammersmithkpa.org.uk and the cost of producing our magazine 'Hammersmith Kidney News'.

Our accounts were approved at the meeting and while we spent just over £1,000 more than we raised in 2002/3 we still

FROM YOUR EDITOR

Welcome to the first newsletter of 2004. Hope you all have a good year.

This is my last newsletter as Editor. Val Said will be taking over from next issue. I would like to thank everyone who has helped me in any way with my the production of the newsletter.

There is plenty in this issue to take inspiration from. I hope some of you will look to take part in some of the events covered this issue or be inspired by Danny Sweeney's example in climbing Ben Nevis, and take on some fund-raising.

Nimrit Foody

had a healthy bank balance of nearly £21,500 as at 5th April 2003.

Don Taylor confirmed that dedicated KPA notice boards have now been put up in the clinics and dialysis units. The KPA now has new distinctive headed stationery and we have renamed our newsletter 'Hammersmith Kidney News' which we hope to distribute three times a year to about 800 patients, all of whom are automatically members of the Kidney Patients' Association. Don Taylor reported that next year we hope to encourage younger members (under forty years of age) to become active in the National Kidney Federation's Young Peoples' Group, and Riminder Dosanjh has kindly agreed to be our Young Peoples' Group representative

In the committee election the main officers who were voted in were:-

President: Gordon Williams
Chairperson: Don Taylor
Vice Chairpersons: Val Said and Nimrit Foody
Secretary: Eileen Parker
Honorary Treasurer: John Bray
Auditors: Kingston Smith (Accountants)

The committee members proposed and agreed were:- Dr Elaine Clutterbuck, Tom Costello, Riminder Dosanjh, Marion Garrett, John Hall, Sarah Kennington, Dr Liz Lightstone, Bhupinder Manz, Margaret O'Neill, Prof. Charles Pusey, Sean Ryan, Carol Toal, and Jan Waters

Prior to the formal business of the meeting a presentation was given by Dr Liz Lightstone. Dr Lightstone spoke about her work on the ABLE Project, which aims to encourage members of ethnic communities to become more aware of the signs and symptoms of kidney disease and to seek early treatment. Liz spoke about the disproportionate incidence of kidney disease amongst the Asian and Afro-Caribbean communities and the actions that can be taken to reduce and treat kidney disease amongst these communities.

Professor Pusey also gave the meeting an update on the progress of the new renal centre. Building works are on schedule with completion due in early 2005. From April 2004 the Renal Department will have its own Shadow Renal Directorate, incorporating both the Charing Cross and St Mary's renal units. The new Renal Directorate will have its own management and staff structure. Professor Pusey hoped that there would be another open evening arranged with KPA members from all the three hospitals.

BENEFIT TIPS

By Val Said

Incapacity for Work Benefit

Most people with a life-long chronic condition do not like to consider themselves as 'disabled'. The main aim is, after all, to get back to living as near normal a life as possible. However, renal failure does have its 'ups and downs' and many patients face financial difficulties because of their incapacity to hold down a job long term. So if this is your current situation, it is important to remember that the benefits system is there to help you. The application forms, however, are not always easy to fill in and there is currently no Social Worker in post at Hammersmith Hospital to give you advice. However, we have put together a few tips which we hope will be of help.

First of all, get the forms. You will need to apply direct to the Department of Work and Pensions (DWP) through your local Job Centre or local Social Security office (the numbers are in the telephone directory). If you are connected to the Internet details of local offices can be found at www.jobcentreplus.gov.uk.

There is also a Benefit Enquiry Line (BEL) - Tel: 0800 882200. This is free from a landline and your call is confidential. The staff cannot deal with specific problems but can give advice on general benefits.

One excellent source of help is the publication: **DISABILITY RIGHTS HANDBOOK** which is published by the Disability Alliance. It costs £14, post and packing are free. It can be obtained by ringing Tel: 020 7247 8776 - or contact your local library to see if they stock a copy.

To give you an example of the invaluable advice given in this book, see the excerpt below.

INCAPACITY FOR WORK - Assessment

If you say you are incapable for work you will need to be assessed by a DWP doctor and fill in a form. The DWP approved doctor will ask you questions about daily living and will get information about your condition by observing you at the examination. For example:

- **Sitting:** watching TV, sitting at meal times or in a car or bus (observing you at the examination).
- **Rising from sitting:** getting on and off the toilet, in and out of the car, out of a chair or off the bed (observing you getting out the chair when they call you in from the waiting area).
- **Walking up and down stairs:** going upstairs to the toilet or bedroom, coping with stairs in shops or, friends' homes, getting on and off public transport.
- **Bending or kneeling:** putting on shoes, getting out of the bath, using a washing machine or low cupboards (observing you bend to pick up a handbag or put on shoes);

TIPS FOR FILLING IN THE FORM: The personal capability assessment - physical disabilities

There are around 12 sections to this assessment and to pass

the test you need a minimum of 15 points in total from all sections. The example first section below will give you an idea of the points that are given for each activity.

1. Walking on level ground with a walking stick or other aid if such aid is normally used

The whole assessment test will be posted onto the KPA website mid February at www.hammersmithkpa.org.uk so do visit the site.

PUBLIC SPEAKING COURSE FOR HHKPA MEMBERS

HHKPA member Adam Ginalski intends to run a Public Speaking course that will include Impromptu Speech, Speech Evaluation and Chaired Meetings. The aims of the course are to give delegates leadership and



communication skills and increase their confidence in expressing themselves.

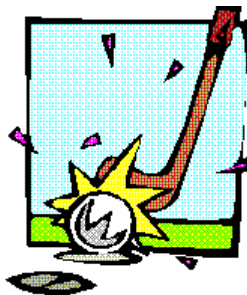
The course will last 8 to 10 weeks, beginning Mid-March onwards although a date is to be confirmed. They will be held on Wednesday evenings at Hammersmith Hospital and last 2 hours. Spaces are limited to twelve, although if there is enough interest, a second course will be considered.

Limited to HHKPA members, the course will cost £50 per delegate. The HHKPA will pay this fee if the delegate agrees to speak on the association's behalf.

If you interested in taking part, please contact Adam on 020 8743 0439.

BRITISH TRANSPLANT GAMES

by Don S Talyor



After you have had a successful kidney transplant for at least six months and it is functioning well it is considered good practice to try and keep yourself as fit as you can and in good physical condition. If you had been a sports person before you had kidney failure and a transplant

or you want to take part in sport, now is the time to begin gentle training with the intention of taking part in the British Transplant Games.

The Games will be held in Norwich based at the University between 22nd and 25th July. The standard of performance is variable but the important thing is to take part in a great and stimulating occasion. There is a large range of sports in the programme including:

ARCHERY, ATHLETICS, BADMINTON, BOWLS, CYCLING, DARTS, FISHING, GOLF, MINI MARATHON, (5km for Men and 3km for Women), SNOOKER, SQUASH, SWIMMING, TABLE TENNIS, TENNIS, VOLLEYBALL and the WALK.

The events are segregated into age groups and there are separate events for men and women.



Any KPA member who has a transplant and interested in knowing more or wanting to take part should contact the Hammersmith Team Manager as soon as possible so you can be sent an application pack.

You should always seek advice from your Doctor or Consultant before embarking on a training programme.

For more information contact the Team Manager, Don Taylor, Tel 01895 445198 or by Email dands.taylor@talk21.com

TRANSPLANT BADMINTON TOURNAMENT

If you have a sound functioning transplanted kidney and you play Badminton there is a tournament for you on Saturday 24th April. It will be held at the Badminton Centre, Walthamstow, East London.



There are various age categories and, as the venue is not far from Hammersmith it is hoped that we will have some players. Interested KPA members (including all Hammersmith patients) should contact Don Taylor (Tel 01895 445198) for more information and an application form.

THE CHALLENGE

By Danny Sweeney



As an experienced mountain and hill walker I have always seen Ben Nevis as the ultimate challenge in the United Kingdom, and being of Scottish origin I thought it was time to go and get it done.

I planned my trip to Scotland for the first week in

August 2003. While I was preparing for my trip I was asked by one of my students, KPA Officer Margaret O'Neill, if I would be prepared to undertake the challenge on behalf of Hammersmith Hospital Kidney Patients' Association and try to raise some sponsorship money.

On the day of the walk the weather at ground level was sunny and warm with great visibility, but this was soon to change for the worse. The walk up the mountain wasn't as strenuous as I thought and good progress was made. The summit was reached in just under three hours and though the weather had changed dramatically this had not deterred the many other hillwalkers who had attempted the ascent on the day.

After spending some time at the top to take photographs I made my way back to base camp where a nice cold beer was the order of the day.

CHRISTMAS DISCO 2003


By Margaret O'Neill

Thanks to the hard work of the organisers, namely Nimrit Foody and Sean Ryan, the Christmas Disco was held on Saturday 13th December 2003 at the Featherstone Hall in Southall. As in previous years patient Steve Thompson provided an excellent buffet (Thank You Steve!) and bar prices were very competitive.

The DJ played a good mix of music that got most people off their seats and onto the dance floor. The Grand Draw was held and there was also a free draw enabling everyone present to have a chance of winning a prize.

One of the highlights of the evening was a group of dancers aged between four and fourteen years. The girls, two of who were the daughters of our organiser Sean Ryan, gave a wonderful and very entertaining display of traditional Irish dancing.

The consensus of opinion is that the evening was most enjoyable, however the lack of support has, following discussion at the last KPA Committee Meeting, rendered it non-viable to hold another Disco in December 2004. The Committee is more than willing to organise a social gathering for its Members and to this end would welcome suggestions for a forthcoming event. To make your suggestions please do not hesitate to contact a Committee Member.



DONOR CARD

One of the roles of the KPA is to "Promote the NHS Organ Donor Register and Donor Card." To fulfil this aim, a copy 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 this to relatives or friends who might become potential organ donors and help save lives.

GRAND DRAW

By Don G Taylor

The Grand Draw was made at the KPA Christmas Party on 13th December. It was a bumper year with the KPA benefiting by more than £2,700. Thanks to all who sold and bought tickets. We hope we can continue to increase the amount raised by this fundraising event annually. If each KPA member, and that includes all patients, could sell one book of tickets we could raise £9,000. This would enable the KPA to provide more specialist equipment and services to benefit patients.

GRAND DRAW PRIZE WINNERS 2003

First Prize: £250 donated by Wyeth Pharmaceuticals was won by R Jones of Southgate
Second Prize: £150 donated by Wyeth Pharmaceuticals and Chelsea Building Society was won by M O'Sullivan of Southall
Third Prize: A Nokia Mobile Phone donated by Virgin Mobile was won by N Ryan of Hayes
A full list of the winners of all sixteen prizes is available from the editor.

We particularly thank Wyeth Pharmaceuticals, Chelsea Building Society, Sheraton Heathrow Hotel, The Avenue Restaurant and Virgin Mobile for donating the main prizes.

The Editor

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CONTACTS

As you may know, the HHKPA has an official website. For those members who do not have access to the Internet at home, they can visit the website when they are next at Hammersmith Hospital. This service is available free of charge within the Ducane restaurant and Café Bleú. If you are not a regular visitor to the hospital, Internet access is widely available at local libraries. So go ahead and visit the site at:

www.hammersmithkpa.org.uk