

**GUY'S & ST.THOMAS' KIDNEY PATIENTS' ASSOCIATION**

**MINUTES OF COMMITTEE MEETING HELD  
15 JULY 2006**

**Present:**

Trevor Cook  
Kate Cushion  
Philip Anderson  
Teresa Durkin  
Richard Baldwin  
James Duncan  
Laila Patel  
Brint Patil  
Charmian Robins  
Ann Cooper  
Stipo Jurcevic  
Jonathan Agboola  
Caroline Morris  
Peter March  
Maggie Loughran

**In attendance:**

John Scoble

**Apologies:**

David Edwards  
John Benson  
Louise Every

**Minutes of Previous Meeting:**

Minutes agreed as read.

**Matters Arising:**

A play written and produced by Glen Mortimer featuring life waiting for a transplant was very good and well attended.

A leaflet has been produced by UK Transplant answering religious questions – suggestion to include this on website?

KPA have been approached by a lady who is an Orthodox Jew who has to appeal to a Rabbinical court to donate – there are further implications for women and it may prevent orthodox burial – agreed we need more information – may wish to share her experience with newsletter.

Helen O'Sullivan has been carrying out a survey into the needs of patients and particular problems they face. John Scoble commented that an expert patient group offering peer support is now up and running.

National Service Framework – Trevor is to circulate his comments – details on the Department of Health Website. The Wellcome Trust has already done some research on transition and compliance.

Funding for the Modernisation Initiative expires in March 2008.

In-Patient Focus was a questionnaire given to both professionals and patients – one point highlighted was that buying a daily newspaper was important to patients but completely missed off the professional list – perhaps this is something the KPA could become involved with? Suggest delivery of the Metro and other free newspapers to the Wards.

There is an on-going debate between the Executive Officers of the Committee on the future role and projects of the Renal Development Officer.

**The Constitution:**

Following April's meeting a revised Constitution was submitted to the Charity Commission, who replied on 21 June. They have no major objections to the bulk of the changes, but would not agree it as submitted. They propose an alternative wording, which has now been incorporated into the draft. This basically says the same thing, but is just a bit more succinct. We now need to formally adopt this wording in accordance with the Regulations, which must take place at the AGM. We can then submit the final version to the Charity Commission.

Revised version circulated – all in general agreement.

Proposed – Philip  
Seconded – Jonathan  
All in favour

**Financial:**

The Marathon has raised £8,293 so far - £1000 more than last year – £4,208 from Rachel Hilton alone! 75% of the donations were received via [www.justgiving.com](http://www.justgiving.com) which has made it very easy to deal with.

Of the 135 completed questionnaires received regarding membership fees, 126 members have elected to treat their membership fees as donations or wish to continue with standing orders – 4 are deceased and 5 refunds were requested. However, £1,000 in unsolicited donations was also received with the responses. Also 80 e-mail addresses were supplied with the return of questionnaires.

Shares – A full report on the current situation was circulated by Philip.

We have received a Legacy from Derek Collett.  
Gift Aid Tax re-claim of £2,629 has been received from the Inland Revenue.  
The total cost of the re-launch party was £3,800, which was under budget.

**Satellite Units:**

Ann asked for a list of all the Satellite Units, together with addresses and telephone numbers. It was proposed that a member of the Committee be appointed as a point of reference for each of the satellite units to open channels of communication:

Philip – Pembury  
Peter – Forest Hill  
Kate – New Cross

**Transition/Adolescent Patients:**

Trevor suggested having a discussion day where we could get patients to meet carers and professionals with feedback later - please pass any ideas or proposals to Trevor.

**Fundraising:**

Laila is currently in the process of preparing a fundraising schedule for the next 6-12 months ahead. Station collections are becoming more difficult as more rules and regulations have been introduced limiting the number of collections permitted – accordingly our next station collection is at London Bridge on Friday, 13 October 2006.

**Research:**

Stipo gave an update on the research projects.

**Any Other Business:**

Kate's new telephone number is 01322 221912

Caroline asked if it would be possible for the KPA to fund travel, etc in order for her to support a young man just transferred from the children's team, George Newman, who is competing in swimming at the Transplant Games – agreed – contact Philip.

Maggie has been contacted by Rosemary, a Care Assistant at the Guernsey Unit, with a view to meeting with the KPA to enable them to become involved with us. Guernsey Unit is much more closely related to us as we run and employ staff – they do have their own KPA but have difficulty in getting support. This is different to Jersey, who have their own unit and employ their own staff.

This year's NKF Conference is to take place on 13th October in Coventry – looking for any volunteers from the Committee who would like to attend?

Kate – Holiday caravan bookings – may wish to consider whether we keep the Seaford Caravan as it is used for summer holidays only. We have had an approach from King's KPA with a view to discussing joint purchase of a holiday flat for patients' use.

Jonathan asked if there had been any progress regarding appointing a part-time admin person – Trevor is looking into options.

Ann asked how we are going to deal with membership of the NKF now that ours is free– how are we going to supply the NKF with addresses? The membership fee for the NKF is £850 for unlimited numbers. It was agreed that we need to discuss the mechanics of it perhaps by having a broader membership group who indicate that they wish to receive it.

Peter March reminded everyone that the deadline for magazine articles is mid September – he is looking forward to receiving reports and photographs. An article on nocturnal dialysis recently appeared in the Guardian Health Supplement.

**MEETING CLOSED** : **12.00 PM**  
**DATE OF NEXT MEETING** : **TBC**  
**VENUE** : **TBC**