

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

**MINUTES OF COMMITTEE MEETING HELD
22 APRIL 2006**

Present:

Trevor Cook
Kate Cushion
Philip Anderson
Teresa Durkin
Ann Cooper
James Duncan
Laila Patel
Brint Patil
Charmian Robins
John Benson
David Edwards
Jonathan Agboola
Stipo Jurcevic
Peter March

In attendance:

John Scoble
Brian Cushion

Apologies:

Richard Baldwin
Caroline Morris

Minutes of Previous Meeting:

Pembury redecoration is now going ahead.
Lord Biffin – meeting did not go ahead as he was unwell – waiting for rearrangement.
Minutes Agreed as read.

Transplant Games – We are to sponsor the Hall Sports - KPMG donated £250
Shares – a report to be circulated by Philip

Philip's Sub-Committee:

Philip has circulated a revised Constitution for discussion. The Charity Commission are interested mainly in only a few things – changing names or objectives or winding up – only these need prior consent – appointing an Honorary President, changing meeting frequency, offering free membership, etc does not required consent.

If anyone does not have any comments or objections then the Constitution is passed as agreed. 1400 are to be mailed out via the Unit – Simon Jeffers is the contact there. Trevor is shortly to mail out a letter – agreed to add questionnaire to save postage.

Question arose – how will we deal with the existing membership within the free membership remit – Philip has produced a 1-page questionnaire to be sent to all paid up members including the following options:

- Donate their membership fee and enjoy future free membership;
- Continue with any standing order and treat it as a donation;
- This will be cost-effective
- They will also be able to access the Newsletter online

Stipo's Sub-Committee:

Research – contribution to website has been discussed.

A new initiative for funding, such as a new scholarship, perhaps the Alec Schwartz Fund? We need to decide on the amount and length of time for it to run – in 8 weeks' time max we could have something up and running.

Medical research – a grant is being applied for in other spheres by Steve Sachs.

Philip summarised financial aspects of current research support.

Funding of Tony Farrer is ending in June 2006 – this is currently paid by standing order – do we cancel this? Agreed we do need feedback from Tony.

Sarah Agboola Research – ongoing

Manesh – the project for paediatric blood pressure monitoring is now up and running.

Agreed that the KPA wishes to support projects rather than individuals – there is a budget and properly structured proposals are welcomed for discussion. We will ask Steve Sachs to come to the next meeting.

Kate's Sub-Committee:

This Committee hope to meet soon.

Chair's Report:

Trevor elaborated upon his written report.

He proposes that we work closely with Kings, who have now offered us use of their holiday facilities in Spain and a caravan in the UK.

He has met with Guy's Charity (formerly the Charitable Foundation) – the KPA is a large organisation – the Charity could offer professional services which could be bought in, such as communication/secretarial/administrative - Trevor asked for comments:

Stipo – Guy's Charity is still not working in a very efficient way and still has some way to go.

Philip – what expertise would we be buying in?

There is a Patient Amenity Fund which John Scoble manages

A discussion of options took place - Trevor suggested that we could appoint a part-time chief executive, a secretary to support (update notice boards etc), offer an ex-gratia payment to the Chair with secretarial support - there is a lot of money involved and we have to take strategic decisions - we could buy in specifics
We need to keep a discussion going.

Jonathan – is there any evidence that what we are presently doing is not right? Do we need something else?

Evelina Children's Hospital – 25th Anniversary Project focusing on younger people – asking what they think about transition – supporting not only the transfer from children's services to adult but from child to adolescent – is there a need for teenage or adolescent units? Discuss self-management and empowerment.

A Spiritual Questionnaire is planned to be sent out go out with newsletter

Vice-Chair's Report:

Kate has visited the Evelina Children's Hospital and Kings with Trevor.

The production of Metamorphosis at the Bromley Little Theatre was successful – we made £350, which was not as much as last year – discussion of timing, promotion and advertising – the weather was not good on the day.

Financial:

Laila organised a successful Cannon Street Station collection - many thanks.

We paid for Maggie's salary with our investment interest.

Paediatric Department are now preparing a budget to avoid any last-minute requests for funds - we can then plan ahead.

Transplant Games - Richard Bennett (Manager of Adult Team) has approached us for funds again – we gave £2,500 last year and there were 8 competitors. Agreed to fund £3,000 this year as there are 11 competitors.

It was considered that future requests should not be made on an ad hoc basis – a planned budget should be set up so that requests such as the above and Ronald McDonald House can be dealt with.

25th Anniversary and Re-launch:

Brian Cushion has produced posters for the re-launch

The Newsletter will be published in time for the re-launch – is going to be in A4 form, with a print run of 2,500. It may be possible for the printers to mail out the newsletter at cost, but Brian is unsure as to how much this will be.

Founder members of the KPA will be invited, together with Chairs of other KPAs in the region. There will then be a ballot for 100 tickets.

John Scoble will be writing to every single patient, including new patients, enclosing an introductory letter from Trevor

Jason Davis has designed our new logo free of charge and has negotiated printing of stationery at cost - £204 in total for large supplies of business cards, compliments slips, letter-head, etc

Our logo will also be electronically available – James will have the stock delivered to his home address.

Our current database will now become redundant.

Fundraising:

Laila has been busy arranging collections – the last one at Charing Cross raised over £1,000 – with more coming up

Philip will prepare a list of donations for the newsletter.

Links with the Modernisation Initiative:

The Modernisation Initiative is coming to an end in 18 months time – Trevor would like to invite representatives along to the Committee to advise on what they are doing – matters raised have included the link with high blood pressure and awareness in the community. They have a website - www.Mykidney.org – where one can register to attend meetings.

Any Other Business:

The New Cross Satellite Unit is due to open on 6 June 2006 and King's is due to open their Satellite Unit in Bromley on 6 August 2006 – patients will be able to transfer to a unit which is more appropriate – John Benson volunteered to take photos for the website.

MEETING CLOSED : 12.30 PM
DATE OF NEXT MEETING : 15 JULY 2006 AT 10.30 AM
VENUE : RENAL SEMINAR ROOM, 4TH FLOOR
THOMAS GUY HOUSE