

**Minutes of UK PIN Steering Group Meeting
Held on 22 July 2003 at the MRC Clinical Trials Unit
222 Euston Road, London NW1 2DZ**

Present: Dr Helen Chapel (Chair)
Dr Tim Wallington (Treasurer)
Dr Gavin Spickett (Secretary)
Sister Fran Ashworth
Sister Teresa Green
Dr Matthew Helbert
Dr Alison Jones
Dr Clive Dash

Apologies: Dr Richard Herriot
Dr David Webster
Dr Amolak Bansal
Dr Carrock Sewell
Dr Graham Davies
Dr Andrew Cant (representing MAP)

MATTERS ARISING

Agenda Item STC/05/03 – Protocols	Action
Dr Helbert reported that there still have been no comments received. Another 8 guidelines were waiting to be uploaded. Discussion about their possible linkage to the Royal College of Physicians a site for evidence based guidelines. A question about patient involvement was also raised.	Dr M Helbert
Agenda Item STC/06/03 – Web Site Development	Action
It was agreed that the committee supported the costs as proposed by Dr Sewell of £100 per calendar month.	Dr H Chapel Dr C Sewell Dr T Wallington
Agenda Item STC/08/03 – Selective IgA Deficiency	Action
Doctors Lilic and Carrock to liaise with the Transfusion Service to produce a new guideline.	Dr T Wallington
Agenda Item STC/03/03 – Pilot Accreditation	Action
Revised (v.6) version of Standards now produced. These to be uploaded onto the website. Expressions of interest have been received from Cambridge and Bristol.	O Bryce
Responses to previous accreditation visits still required from St Bartholomew's and the Royal Free.	O Bryce
The spreadsheet of failures by standards is being organised by Olga and this will need further development as more inspections take place.	
Dr Jones reported that the outcome of inspection had not favourably impressed their Chief Executive at GOS. Dr Jones to contact CE again and then liaise with the Chairman.	Dr A Jones Dr H Chapel

Agenda Item STC/04/03 – Roll-out	Action
<p>Further information is going to be required on a number of sites to be visited in order to define charging structures. It was agreed that while expressions of interest remain low we should continue on a voluntary scheme without introducing charges. It was felt that we would need to be close to UKAS standards before launching a paid scheme.</p>	
Agenda Item STC/15/03 - Revised Standards	Action
<p>Standards and guidance was then taken immediately after this. It was noted that the Standards now include a greater guidance and that the application form would be separate. Following comments were raised regarding specific standards:</p> <ul style="list-style-type: none"> • C4 - Facilities would need to be available for patients unwell during an infusion. • D2 - Protocols should include a comment relating to development for local services • D5 - Additional comment – databases should be registered under the data protection legislation • E7 - Requirements for Epipens will be reviewed. • B3 - Add as per local arrangements. <p>The Training Day has been organised for 10 September 2003 and a draft programme has been produced.</p> <p>CPD accreditation is required for doctors and nurse.</p> <p>It was agreed that Jose Drabwell from the PiA should be invited as an observer to the process.</p> <p>It was agreed that if people have problems with travel expenses, the consultant and nurse exchange fund might be used to support this. It was also agreed that there might be a need for a non-London Training Day.</p>	<p>Sister F Ashworth Dr G Spickett O Bryce</p>
Agenda Item STC/09/03 – Register	Action
<p>It was reported that Dr Davies is now piloting a database for BMT patients with between Newcastle and Great Ormond Steet. Data manager is now in post and compatibility of databases with the ESID database has been assured. Hardware and software exist and some funding from industry has been obtained.</p>	
Agenda Item STC/11/03 – Periods in Office	Action
<p>It was noted that the Chairman, Dr Chapel has indicated that she wishes to step down by January 2004. It was agreed that there should be 4 yearly terms of office with an orderly retirement of existing officers such that the Treasurer will step down in January 2005 and the Secretary in June 2004. It was agreed that job descriptions would need to be produced and that nominations for these posts should be put to the UK PIN meeting in York for a ballot.</p>	

It was also agreed that other STC members need to step down by rotation including David Webster, Graham Davies, Amolak Bansal and Teresa Green early in 2004. It was noted that Richard Herriot has his place ex-officio as Chairman of the ACP Immunology Committee that Andrew Cant has his post ex-officio as Chairman of the PiA MAP.	Dr G Spickett
Agenda Item STC/12/03 – Report for BPL	Action
The draft report was reviewed. This did not identify the budget breakdown across the different areas of activity. New business case is needed before October 2004 for funding beyond January 2005.	Dr T Wallington
It was agreed that a draft Constitution should also be sent out for comments to Steering Committee members and posted on the website for comment.	Dr Carrock Sewell O Bryce
Agenda Item STC/12/03 – Treasurer’s Report	Action
The Treasurer presented the current financial position for UK PIN. It showed a favourable surplus at present. However, funds have been committed to the website and the training days.	
Agenda Item STC/14/03 – Quality of Life Survey	Action
Dr Helbert reported this was a study of psychosocial functioning in CVID. Conclusions indicated considerable degree of anxiety which was worse in young adults and identified the need for training. Counselling in an increase in psychology support to CVID patients. It was agreed that some of the exchange funding might be used to support this.	
Date and Time of Next Meeting	
The next meeting will be held at 9.00 am on Friday 7 November 2003 at the Immunology Forum in York.	