

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

Present: PiA

Jose Drabwell
David Watters

UK PIN

Gavin Spickett
Helen Chapel
Teresa Green
Matthew Helbert
Clive Dash (BPL)
Fran Ashworth
Alison Jones

Apologies: PiA

Clare Tritton

UK PIN

Amolak Bansal
David Webster
Carrock Sewell
Graham Davies
Andrew Cant
Tim Wallington
Richard Herriot

Chairman welcomed Dr Clive Dash from BPL and Jose Drabwell from the PiA to their first meeting.

Agenda Item PIA/02/03(a) - <i>Consent Form – Patients’ Views</i>	Action
<p>PiA raised concerns that during the consent process patients will be given enough information on infectious hazards. Suggested a national model incorporated in the UK PIN Guidelines might be appropriate and the PiA Trustees were invited to comment directly on the website. Suggested that it might be helpful for the patient information leaflet incorporated with each bottle of immunoglobulin be given to the patients. Dr Helbert reported during his quality of life study 37% of patients were concerned about risks of HIV indicating that the information given to them was inadequate.</p> <p>Dr Dash agreed that SPC is of limited value as EMEA control the information to be included.</p>	<p>F Ashworth (UKPIN) T Green (UKPIN)</p>

Agenda Item PIA/02/03(b) - <i>Sample Register – Look Back</i>	Action
<p>Doctors Eglin and Anstee have been asked to look again at feasibility of archiving samples case of a new blood contaminant. Dr Helbert will write to Dr Eglin and ask again if a host of PID patients could be included. Dr Helbert reported his back study in relation to IVIg use had gone to the Department of Health (DOH) for his survey of IVIg recipients receiving batches from suspect doses of SNBTS and Vigam products. Tissues will go to the Research Centre at Edinburgh. There has been no news on this proposal. The risk assessment has now been revised by the DOH. Concerns were raised about adequacy of training in relation to the DOH's plans for the identification of recipients who have received suspect batches in relation to their subsequent medical care. DOH has now put a hold on their final report which is not now expected until 2004.</p>	<p>M Helbert (UKPIN) H Chapel (UKPIN) D Watters (PIA)</p>
Agenda Item PIA/02/03(c) – <i>Specialist Commissioning</i>	Action
<p>It was noted that there had been some progress in London with regular quarterly meetings although the proposals were expected to be cost neutral. A strong role was identified for the nurses in the London Commissioning. Responses from around the country seemed to be variable. A survey will be carried out.</p>	<p>H Chapel (UKPIN) O Bryce (UKPIN)</p>
Agenda Item PIA/02/03(d) – <i>HAE Consensus</i>	Action
<p>Meeting to be held on 25 July 2003 in Bristol organised by Dr Gompels to take forward the production of a consensus document.</p>	<p>D Watters (PIA)</p>
Agenda Item PIA/05/03 – <i>Website</i>	Action
<p>Proposals have been received from Dr Sewell regarding professional support for website at a cost of £100 per month. Approved and Dr Wallington to set up final agreement.</p>	<p>H Chapel (UKPIN) C Sewell (UKPIN) T Wallington (UKPIN)</p>
Agenda Item PIA/02/03(f) – <i>York Meeting</i>	Action
<p>Dr Spickett reported on the programme for the meeting. It appeared that Dr Dash and the PiA had not received copies of the programme. Dr Helbert raised the point that speakers would need to be reminded of the existence of the guidelines and asked to ensure that their talks were centred around this.</p>	<p>O Bryce (UKPIN) G Spickett (UKPIN)</p>
Agenda Item PIA/03/03 - <i>Consultant and Nurse Exchange</i>	Action
<p>Sister Green indicated that the RCN nursing group did not appear to be interested in promoting this scheme at present. They has been one application from a nurse from Aberdeen to attend in Newcastle which has been approved. It is clear that if there are nursing applications, one of the nursing members of the steering committee would need to vet applications.</p>	<p>T Green (UKPIN) F Ashworth (UKPIN) T Wallington (UKPIN) R Herriot (UKPIN)</p>

There have been no applications from consultants. It was felt appropriate for the steering committee chairman to approach single handed consultants to encourage them to take up the offer.	H Chapel (UKPIN)
Agenda Item PIA/04/03 – Patient Input to Accreditation	Action
<p>It was agreed that the current document needs amending. Prior study of a revised version with patients in Oxford had disappointing results. It was noted that Sister Freud had produced a more user friendly document. It was agreed that nurses should work to produce a revised version.</p> <p>It was agreed that the process for analysis and transmission of questionnaires to the assessors needs to be reviewed. Question of patient assessors was discussed. It was agreed that in principle this was a good idea although the time required, when the trustees are already overloaded, would need to be considered carefully.</p>	<p>T Green (UKPIN) F Ashworth (UKPIN)</p> <p>D Watters (PIA)</p>
Agenda Item PIA/08/03 – IVIg Tendering (PASA)	Action
This has now been undertaken, although no information was available to the committee on the effects that the process had had. It was agreed that some form of information is required for the newsletter and the website.	A Jones (UKPIN) G Spickett (UKPIN)
Agenda Item PIA/09/03 – Primary Antibody Deficiency Consensus	Action
Reported that some progress had been made, Dr Bansal and Dr Ibrahim involved in advising re format and process. It was noted that the Joint Committee for Immunology and Allergy of the Royal Colleges of Physicians and of Pathologists wanted to be involved in the scheme and had identified representatives (Dr Phil Wood and Dr Mike Dudderidge). It was also noted that the RCP was interested in having the consensus on the RCP website. The next meeting for the consensus group will be in Leicester. It was noted that representatives from organisations previously involved (British Thoracic Society, Royal College of General Practitioners, PIA, Royal College of Nursing, Royal College of Paediatrics and Child Health) all needed to be involved. It was accepted that there will be some overlap with the protocols group and Dr Helbert will represent this group.	H Chapel (UKPIN)
Agenda Item PIA/10/03 – Research in CVID	Action
Dr Chapel reported on the outcome of the process which had arisen from the meeting currently organised at Coughton Court by Mrs Claire Tritton. Dr Chapel and Dr Hammarstrom had been to discuss proposals with Mark Walport, the new Director of the Wellcome Trust. Though the Trust agree that CVI is an interesting condition(s), it is unlikely that any ring fence funding would be available. It had, however, been a useful meeting in raising the profile of primary immunodeficiency research at a high level. There was of course, significant benefit from getting interested individuals around the table at Coughton Court to discuss collaborative proposals.	Steering Committee

Agenda Item PIA/12/03 – <i>Any Other Business</i>	Action
<p>It was reported that the PIA valued UK PIN as an organisation and that it was important for the Trustees to have an input into UK PIN. Relationship of the Medical Advisory Panel of the PIA to the Steering Committee of UK PIN was discussed and it was agreed that these should be kept separate. The chairman of the MAP will be an ex-officio member of the UK PIN Steering Committee. It was noted again that the PIA’s Medical Advisory Panel had no nursing representatives and the recommendation that this be corrected was agreed.</p>	<p>D Watters (PIA)</p>
Date and Time of Next Meeting	
<p>To be agreed.</p>	