

**Minutes of the UK PIN Steering Group Meeting
Held on Monday 8 May 2006
At the Royal Society of Medicine
1 Wimpole Street, London, W1G 0AE**

Present:

Richard Herriot – Chairman
 Carrock Sewell – Secretary
 Dinakantha Kumararatne – Treasurer
 Chris Hughan – PiA
 Fran Ashworth
 Andrew Cant
 Cilla Freud
 Bridget Heelan
 Lucia Russell
 Joe Unsworth
 Sheila Cochrane, Cathy Cale & Mike Duddridge (in attendance from the Accreditation Committee)
 Olga Bryce

Apologies:

Terry Flood
 Matthew Helbert
 Phil Wood

Richard Herriot welcomed Bridget Heelan as a new member of the UK PIN Steering Group.

1. Previous meeting	Action
The minutes of the previous meeting held on 19 November 2005 were accepted as a true and accurate record.	
2. Matters arising	
<p>2.1 Choose & Book</p> <p>One PID centre had reported difficulty with the new arrangements for C&B, but Richard Herriot reported that, following discussions with a contact in the DoH, it may have been that the local C&B ‘rules’ in the Directory of Service had not been set correctly. UK PIN members should ensure that their local rules are appropriately</p>	

<p>set to reflect their expertise and services offered. Richard Herriot is interested to hear of any ongoing problems PID centres may have with either C&B or Payment by Results.</p> <p>2.2 Commissioning arrangements</p> <p>Richard Herriot reported that he had now received details from many, but not all, UK Immunology centres regarding the status of local commissioning for PID services. He will be producing a document describing the status of commissioning around the UK in due course (though this can not be entirely comprehensive).</p> <p>2.3 Document control</p> <p>Olga Bryce reported that the Q-Pulse document control system is now set up in the Newcastle UK PIN office, and she has now been trained in its use. The system will be commissioned with the update of the new accreditation standards.</p>	<p>R Herriot</p> <p>O Bryce</p>
3. Accreditation	
<p>The Accreditation Committee gave a verbal report of its deliberations, noting that it was agreed to move the accreditation scheme from pilot to substantive status. All centres, as a minimum, will be asked to register their intent to be accredited – this will provide valuable information regarding the number of centres, staffing levels, approximate patient numbers and investment needs in the UK. On-site inspections will be restricted to centres which pass a review of the self-assessment documentation, as well as a satisfactory review of paperwork undertaken prior to the visit. It was noted that self-assessment processes were currently popular with a variety of regulatory bodies. Centre status will therefore be either (a) not in the scheme, or (b) registered and self-assessed, or (c) inspected and conditionally or fully accredited.</p> <p>A written report regarding the new standards will be produced by Joe Unsworth.</p>	<p>J Unsworth</p>
4. Finance	
<p>4.1 Current financial position</p> <p>The current financial position shows expenditure of approximately £3,500 last financial year, approximately one third on expenses, one fifth on the Steering Group, one quarter on producing the</p>	

<p>Consensus Documents, with the remainder consumed by on-site visits. The current audited balance at the end of Financial Year 2005 was £21,279. The mean cost of an on-site visit is to be calculated by Kumar.</p>	<p>Kumar</p>
<p>4.2 Administrative assistant</p> <p>It was agreed to extend Olga Bryce's contract by a further year.</p>	<p>Kumar</p>
<p>4.3 BPL Sponsorship</p> <p>Sponsorship from BPL ceased at the close of FY2005. Richard Herriot will formally thank BPL for their support.</p>	<p>R Herriot</p>
<p>4.4 New sponsorship arrangements</p> <p>A proposal for sponsorship by ZLB Ltd was tabled, which would support UK PIN with £20,000 over two years, starting 1 July 2006. In return, ZLB expect their logo on the UK PIN website, the ZLB logo on UK PIN correspondence, access to the UK PIN online members list (which is already in the public domain), and the Steering Group to act as a Medical Advisory Board (meetings to be arranged to follow regular Steering Group meetings). The officers of the NHS Grampian Clinical Governance Committee have reviewed this proposal and agree that it is robust and defensible. The Steering Group noted that they had already followed the Clinical Governance Committees recommendation that all other companies should have been asked for sponsorship (none was forthcoming from other companies). Furthermore, the Steering Group members noted that membership of this Medical Advisory Board should be declared in any relevant declaration of interests, although recognising that there is no pecuniary advantage to individual Steering Group members by such sponsorship.</p>	<p>All Steering Group Members</p>
<p>This proposal was accepted by the Steering Group (including Matthew Helbert and Phil Wood in absentia through prior telephone discussion with Richard Herriot).</p>	
<p>Carl Wheeler (ZLB) will liaise with Olga regarding camera-ready artwork of the ZLB logo, and with Mike Laycock regarding putting the logo on the UK PIN website. Carrock Sewell was tasked to harmonise the various UK PIN logos which have been used on the website and letter heads, and to commission a supply of UK PIN headed paper in colour.</p>	<p>O Bryce M Laycock C Sewell</p>

5. Links with BSI	
<p>Discussion regarding possible links with the British Society for Immunology (as discussed with all UK PIN members at Immunology Forum 2005) has not progressed. No formal decision regarding the desirability or otherwise of this link was reached by the Committee. Further information from the CEO of BSI is awaited.</p>	
6. Consensus documents	
<p>6.1 Consensus document for managers</p> <p>For completion, this document has had a section on Payment by Results added. The Steering Group agreed that this document should be launched at high level with the the DoH. Richard Herriot and Chris Hughan will discuss the best approach.</p> <p>6.2 Diagnosis and Management of Antibody Deficiencies</p> <p>The Writing Group, together with the Cochrane Group, continues to examine and grade the existing evidence upon which this document will be based. Individual UK PIN Members were reminded that they may be asked by the Writing Group to assist with this process.</p>	<p>R Herriot C Hughan</p>
7. UK PIN Membership	
<p>There are currently 172 members of UK PIN.</p> <p>The Steering Group noted the proposals to update and refresh the design of the website.</p>	<p>C Sewell M Laycock</p>
8. Steering Group	
<p>The Steering Group noted that Fran Ashworth will demit office in November, and Andrew Cant in late 2006. Richard Herriot will check the current status of Steering Group members and ensure that the correct list is available on the website.</p>	<p>O Bryce R Herriot</p>
9. Guidelines	
<p>It was noted that several UK PIN Guidelines are now out of date. The Chairman of the Writing Group has not yet taken up his post because of other commitments. Cilla Freud and Cathy Cale agreed</p>	

<p>to review the status of the current guidelines. The Steering Group recommended that the Writing Group consider the role of the AGREE criteria for the production of new (and new versions of) UK PIN Guidelines.</p>	<p>C Cale C Freud</p>
<p>10. Databases</p>	
<p>The current status and utility of the ESID Database was discussed. Chris Hughan (PiA) outlined how useful it would be to have at least a register of the number of each type of immunodeficiency patient in the UK, and emphasised that the PiA would be willing to help give financial support for this. This could involve funding a dedicated data entry person.</p> <p>Steering Group members discussed the difficulty in gaining ethical approval at each centre (even though MREC approval has been obtained), the complex practicalities of obtaining consent from each patient, and the time-consuming nature of data abstraction and entry. Concern was also expressed regarding the involvement of drug companies in the ESID database, and their sole access to the entire data set. Comparisons were made with the current UK cystic fibrosis database, which appears to be easier to use, and to address more relevant clinical questions.</p> <p>The existing databases for paediatric (transplantable) immunodeficiencies were noted, and how they could currently link with the ESID database, although these databases are not currently being maintained. It was agreed that simple aggregate data (numbers of each condition in each centre) would be very valuable, and that this information would be useful for both UK PIN and the PiA. Richard Herriot and Chris Hughan agreed to meet to discuss the way forward in more detail, as well as to formulate a core team of relevant individuals, which should include Bodo Grimbacher (when he takes up his post at the Royal Free) and Graham Davies.</p>	<p>R Herriot C Hughan</p>
<p>11. Grifols subcutaneous immunoglobulin</p>	
<p>Concern was expressed regarding Grifols recent announcement about withdrawal of its (unlicensed) subcutaneous product. A number of patients in the UK use this product, but now that three licensed subcutaneous products are available, the MHRA has mandated that unlicensed products should not be used. The PiA and individual UK PIN members had fielded significant concerns from patients and immunology staff about the timing and method of communication regarding this product withdrawal. Following</p>	

<p>discussions between the MHRA and the PiA, it transpired that importation would still be possible “if there are pressing reasons for doing so”. It was noted that Grifols have agreed that patients may keep their syringe driver pumps. Richard Herriot has written to the MHRA and Grifols outlining the non-desirability of immunoglobulin product change, and emphasising the need for a well-planned change-over process.</p>	
<p>12. Lincoln Immunoglobulin Centre</p>	
<p>Carrock Sewell reported that the Lincoln University Centre for Immunoglobulin Therapies (exact name to be confirmed) was still being developed, and had received expressions of support from several immunologists in the UK and abroad, who were interested in participating. Lincoln University was still in the process of approving the concept of a virtual research centre, but initial discussions were very positive. Carrock will continue to keep the Steering Group updated with progress in this area, and would like to continue to hear from UK PIN members wanting to contribute.</p>	
<p>13. Links with Canada</p>	
<p>Carrock Sewell reported that both the Canadian Immunodeficiency Patients Organization (CIPO) and Canadian immunologists were extremely interested in UK PIN and how to establish similar networks in Canada. Carrock has already addressed several meetings in Canada regarding the role of UK PIN. Following expressions of interest by the Steering Group, Carrock will look into possibility of setting up a joint meeting with a Canadian PIN at some point in the future.</p>	<p>C Sewell</p>
<p>14. Any other business</p>	
<p>14.1 Immunology Forum Arrangements for the next Immunology Forum meeting were discussed. It was agreed to ask Aarn Huissoon to chair the Organising Committee for this next meeting.</p> <p>Cilla Freud was concerned that formal proceedings of the last Immunology Forum had not been published, and the Steering Group agreed that this should be done in future to make the meeting more useful. Kumar noted that, unlike the AAAAI meetings, there was little involvement of the membership in determining the content of the meetings. Richard Herriot agreed to ask the Forum Organising Committee to undertake this.</p>	<p>R Herriot</p> <p>R Herriot</p>

<p>14.2 Links with PiA</p> <p>The Steering Group agreed that Chris Hughan should continue to attend Steering Group meetings as his advice, and links with the PiA were invaluable. Chris updated the Steering Group on the organisation of the PiA, which has recently had several changes of core staff, as well as changes to the Medical Advisory Panel, the Peer Review Panel, as well as the Trustees. Ways of sharing organisation structure and administration were being considered. Given that 60% of the income from the Jeans for Jeans campaign that goes to the PiA goes to research, it was important that appropriate administrative and organisational structures were in place.</p>	
<p>15. Next meeting</p>	
<p>Following consultation with Steering Group members, Olga Bryce will set a date for the next meeting in September.</p>	<p>O Bryce</p>