

**Minutes of the UK PIN Steering Group Meeting  
Held on Saturday 19 November 2005  
in the Reading Room, Royal York Hotel, York**

**Present:**

Richard Herriot – Chairman  
Carrock Sewell – Secretary  
Dinakantha Kumararatne – Treasurer  
Fran Ashworth  
Andrew Cant  
Cilla Freud  
Matthew Helbert  
Lucia Russell  
Joe Unsworth  
David Webster  
Phil Wood

**Apologies:**

Alison Jones

<b>1. Previous meeting</b>	<b>Action</b>
The minutes of the previous meeting held on 20.6.05 were accepted as a true and accurate record.	
<b>2. Matters arising</b>	
<p><b>2.1 Adverse reactions to immunoglobulins</b> Ruth Weldon has circulated a reminder to the RCN Nurses Group that adverse reactions to immunoglobulin should be reported using the Yellow Card system.</p> <p><b>2.2 Interaction with PiA</b> Ruth Weldon kindly obtained information from 14 PID centres about the numbers of patients seen in each centre, and this information has been forwarded to the PiA.</p> <p><b>2.3 New immunoglobulin manufacturer</b> Biotest have reported that they will be marketing a new immunoglobulin product in the UK next year.</p>	
<b>3. Accreditation</b>	
<p>There are no applicant centres currently awaiting visits for accreditation assessment.</p> <p>A new draft accreditation application document for (version 7.0) has been prepared, to include a self-assessment section. This and</p>	
<p>other related accreditation documents (Inspector/Applicant Centre Manual and Assessment Protocol) are now nearly complete. The final drafts of these documents will be ratified by the Accreditation Committee and circulated among the Steering</p>	<p>J Unsworth R Herriot</p>

<p>Group members before posting on the website.</p> <p>The Group agreed to move the accreditation process from the current pilot phase, to a substantive accreditation process. It was agreed that those centres that were accredited in the pilot phase should be granted formal accreditation until the four-year term of their accreditation expires. The Group rejected charging a set accreditation fee to new centres, since it was felt unlikely that NHS Trusts would be willing to identify resource for this, at least at present, and also because this would not be a process on which future funding of UK PIN could be robustly structured. However, direct expenses incurred should be recouped and it may be possible to construct a generally applicable single accreditation fee, covering such direct expenses, for all centres if costs were approximately the same. There would be no element of income generation from this process. Kumar will identify direct costs arising from recent accreditation visits in relation to this. He requested that expenses for accreditation issues should be marked as such on claims so that these can be identified and accounted for separately. The Group noted that Olga Bryce is being trained in the QPulse document control system.</p>	<p>D Kumararatne</p>
<p><b>4. Consensus documents</b></p>	
<p><b>4.1 PID For Managers</b></p> <p>This document is almost complete and was well received. A paragraph on Payment by Results is awaited from David Webster. It was noted that all immunoglobulin (for hospital or home therapy) will be paid for by Primary Care Trusts from April 2006. A consensus stakeholder meeting relating to the Managers' document is to be organised by the PiA in London.</p> <p><b>4.2 Consensus on Diagnosis &amp; Management of Primary Antibody Deficiencies</b></p> <p>The literature base for this project has now been obtained and review/scoring is underway. The document will be too large to comply with the Royal College of Physicians mechanism for development and publication of Concise Guidance to Good Practice, so will be published as a separate systematic review and thence developed into formal RCP Guidelines.</p>	<p>D Webster</p> <p>P Wood</p>
<p><b>5. Finance</b></p>	
<p>The current balance is in credit at approximately +£30,000. Recent outgoings were approximately £3,000. The Treasurer agreed to circulate the accounts on a monthly basis to the Steering Group. It was noted that the Webmaster has not been paid for several months now, and Kumar agreed to chase this up. It was agreed that the webmaster's contract be extended for a further year. Olga Bryce will copy the old contract to Richard Herriot for updating. The Group noted that no further offers of sponsorship had been obtained.</p>	<p>Kumar</p> <p>O Bryce</p> <p>R Herriot</p>
<p><b>6. Membership</b></p>	
<p>There are currently 163 approved and registered members of UK</p>	

PIN.	
<b>7. Steering Group Membership</b>	
<p>Alison Jones demits office at this meeting, and was thanked (in her absence) for her input to the Steering Group. The Group asked Richard Herriot to approach Terry Flood as a replacement Paediatric Immunology representative.</p> <p>Andrew Cant will continue as the PiA MAP representative, as he will be chairing that body until late 2006.</p> <p>With his impending retirement, David Webster demits as the London Immunology representative, and was thanked for his considerable input to the Steering Group, and Clinical Immunology in general. The Group asked Richard Herriot to approach Bridget Heelan as a representative of London immunologists.</p>	<p>C Sewell to write.</p> <p>R Herriot</p> <p>R Herriot</p>
<b>8. Guidelines</b>	
The Steering Group noted that the Guideline Writing Group will hope to actively restart the Guideline review process, and writing new Guidelines, in Spring 2006.	
<b>9. Databases</b>	
No news was received in the Steering Group meeting about the status of the ESID database, although delegates received an update from Helen Chapel during the <i>Immunology Forum</i> meeting. UKPIN members are welcome to approach the ESID team to set up access and consent procedures for their centres.	
<b>10. Any other business</b>	
<p><b>10.1 Influenza plan</b></p> <p>The Steering Group discussed the TRIC Influenza Plan, and debated how to plan for an influenza pandemic. It was agreed that primary immunodeficiency patients should be offered influenza immunisation, on the grounds that any form of protection, however slight in these patients, would be useful, and would be unlikely to cause harm. The TRIC proposals to obtain prophylactic and treatment doses of oseltamivir in advance for primary immunodeficiency patients were discussed. The major limitation is that although these proposals were based on DoH guidance, sufficient supplies of antiviral agents are not available. Some centres also have concerns about the utility of oseltamivir prophylaxis, particularly in children. UK PIN is keen to provide the PiA with a workable solution, so Andrew Cant and Carrock Sewell will meet to construct simple national guidance relevant to primary immunodeficiency patients. All Steering Group members were encouraged to send suggestions to Andrew Cant and Carrock Sewell.</p> <p><b>10.2 Lincoln University Centre for Immunoglobulin Research</b></p> <p>Carrock Sewell outlined plans for the launch of a virtual centre for immunoglobulin research based at the University of Lincoln. Although only in the planning stages at present, the proposed</p>	<p>A Cant</p> <p>C Sewell</p> <p>All</p>

<p>centre would act as a centre for the coordination of research into all aspects of immunoglobulin therapy, including nursing, immunology, pharmaceutical, etc. The hope is that this would provide a contact point for all immunoglobulin researchers around the country. The Steering Group was supportive of this concept and it was agreed that the status of the centre should be a standing agenda item in the future.</p>	
<p><b>11. Next meeting</b></p>	
<p>The next Steering Group meeting will be arranged for a convenient date in the Spring of 2006. The Accreditation Committee should also plan to meet on the same date.</p>	<p>O Bryce</p>