

**Minutes of the UK PIN Steering Group Meeting
Held on Tuesday 8 February 2005 in the Club Boardroom
at the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE**

Present: Richard Herriot - Chairman
Carrock Sewell - Secretary
Dinakantha Kumararatne - Treasurer
Tim Wallington
Joe Unsworth
Alison Jones
David Webster
Teresa Green
Cilla Freud
Fran Ashworth
Lucia Russell
Olga Bryce

Apologises: Matthew Helbert
Philip Wood
Andrew Cant

1. Matters Arising from Previous Meeting not on the Agenda	Action
<p><i>1a. vCJD Update</i></p> <p>Matthew Helbert has almost completed an MREC application for a study of vCJD surveillance in PID patients. Development of relevant patient information sheets for this still requires input from the PiA. The Research Nurse job description for the study is almost complete and will be advertised soon.</p> <p><i>1b. Consultant and Nurse Exchange</i></p> <p>No additional claims have been made on this account. £2000 was initially granted to UK PIN by the PiA. Around £600 has been spent to date. Tim Wallington will send a report to the PiA outlining the usage of this fund. It is hoped to encourage greater use of the available resource by improving Network members awareness of its availability. This will be raised again with Immunology nurses at the March meeting in Hull.</p> <p>It was agreed that the fund could be used for consultant exchange visits between centres or Networks to discuss difficult cases or collections of cases (the latter would optimally require good local patient Registries) or for audit group visits. Also agreed that the fund should only be used</p>	<p>T Wallington</p>

<p>when requests for alternative sources of funding (e.g. Trusts etc.) were exhausted or not available. Future applications for funding should be made to Kumar.</p> <p>1c. CPD Bulletin in Immunology and Allergy</p> <p>Ed Kaminski is unable to take up the editorship of the CPD Bulletin. Rila is now planning to merge the Immunology and Infection journals to produce a combined Immunity & Infection CPD Bulletin for which co-editors will need to be identified. This process may disadvantage CPD for the clinical Allergy community.</p>	
<p>2. PID Centre Accreditation Scheme</p>	<p>Action</p>
<p>2a. Standards and Documentation</p> <p>The PID Centre Standards and associated documentation are being reviewed by Joe Unsworth and Richard Herriot. Redundant, replicate or ambiguous standards are now being removed, and issues around quality management are being clarified.</p> <p>It was agreed that these revised Standards will require to be approved by the Accreditation Committee and then be ratified by the Steering Group. Cathy Cale has agreed to represent Paediatrics on the Accreditation Committee. Andrew Exley has indicated his willingness to service as a PID centre assessor for UK PIN.</p> <p>2b Assessment Visits</p> <p>The status of the following centres is as indicated: Plymouth has now been assessed and feedback completed. An action plan for how they plan to address identified shortcomings is anticipated. Sheffield will be inspected in May. Leeds has requested assessment of both adult and paediatric services, so assessment team assembly has been complex and suitable dates are still awaited. Papworth has expressed an interest in assessment, and may consider a Network application with Cambridge. St. Helier have an application pending.</p> <p>The accreditation application form will need to change with the revised standards and new applicants should use the new forms when they are available. The current website form is outdated and needs the self-assessment form to be added as an integral component. Any new applicant centres will be advised to delay their applications until the new documentation is agreed and in place.</p>	

Olga will examine Q-Pulse being used in Histopathology at Newcastle.	O Bryce
3. Consensus Documents	Action
<p>3a. PID for Managers</p> <p>This document is currently waiting for some final clinical vignettes and for a meeting with the PiA Chief Executive and key managerial stakeholders to be organised.</p> <p>3b Update of Antibody Deficiency Consensus Document</p> <p>Andrew Cant has been formally nominated by the RCPCCH as their representative on the UK PIN Development Group updating the 1995 Consensus Document.</p>	
4. Change-over of UK-PIN Treasurer	Action
<p>Kumar has now taken over from Tim Wallington as Treasurer. Tim will be notified when Addenbrookes have established an account and audit mechanism. Tim will continue dealing with invoices and payments until the new account is opened, after which Kumar will formally take over.</p> <p>Kumar will inform Steering Group officers when the new account is ready for transfer of funds.</p>	Kumar
5. Business Case/Finance	
<p>5a. Current Financial Position</p> <p>The current account stands at £25,553.83. There is still £20,000 owed by BPL. Pfizer have pledged £1,000 as a contribution although it was not clear whether this was to be directed toward the costs of the Immunology Forum or is attributable to the general UK PIN finances.</p> <p>Funding for the York meeting will be a separate issue, with an account which is separate from that of UK PIN and is managed by the meeting organisers.</p> <p>5b. Direct Costs of PID Centre Accreditation Visits</p> <p>Tim Wallington agreed to compile a spreadsheet of the direct costs of PID centre accreditation visits to date.</p>	<p>T Wallington</p> <p>T Wallington</p>

<p>5c. Future UK PIN funding</p> <p>Richard Herriot has written to all Immunoglobulin suppliers with a revised business case, requesting their consideration of funding for UK PIN activities over the next few years. The general impression is that this is likely to be attractive to such potential sponsors.</p>	
<p>6. UK PIN Membership</p>	<p>Action</p>
<p>The UK-PIN membership application form is now available on-line. 78 applications have been received, with 77 approved. One application from a PiA Trustee for (continuing) Network membership has been declined by the Steering Group Chairman following discussion with the PiA Chief Executive. Richard Herriot has written to the applicant indicating the reasons for refusal of the application, which are essentially to maintain formal separation of UK PIN and the PiA as distinct organisations. This is also in keeping with the Network constitution. Olga has informed all but a few of the applicants to date that they have been accepted.</p> <p>Olga to send the approved spreadsheet to Mike Laycock for publication on the website. Olga will remind known immunology doctors and nurses who have not yet applied of the new process for membership application. Richard Herriot will check who is our registered data controller under the data protection act.</p>	<p>O Bryce</p> <p>R Herriot</p>
<p>7. Guidelines</p>	<p>Action</p>
<p>7a. Guideline Writing Group</p> <p>Carrock Sewell has resigned from the Guideline Writing Group, and Matthew Helbert has stepped down as leader, but wishes to stay with the group. Philip Wood has agreed to lead the Group once the work in producing the consensus document update has been completed. Current writing group members are Cilla Freud, Matthew Helbert, Philip Wood and Cathy Cale. Desa Lilic has also indicated her willingness to contribute and Richard Herriot will write to her formally inviting her to join. Other (medical) individuals have indicated in the past that they would also welcome involvement in UK PIN activities and may be asked to join the Writing Group if necessary. More nurses are urgently needed and it was agreed to discuss this in more detail at RCN meeting in Hull. Teresa Green indicated that she is happy to be involved in the Writing Group although she is leaving the Steering Group.</p> <p>It was noted that the website has been receiving a significant number of hits, but concern was expressed regarding the relative lack of</p>	<p>R Herriot</p>

<p>feedback regarding posted Guidelines that members are returning to UK PIN via the website. In spite of this the importance of the Guideline construction element of UK PIN was emphasised and strongly felt by Steering Group members. Members have received a significant amount of anecdotal support about posted guidelines.</p> <p>All Steering Group members to consider suggestions for nursing representatives on the Guideline Writing Group, particularly following the next meeting of the nurses group in Hull. Olga to investigate and report on the number of feedback emails and approval emails received from the website in regard to posted Guidelines.</p> <p>7b. Home Therapy Guidelines</p> <p>Thanks were expressed to Fran, Lucia, Teresa and Sheila for updating the national Home Therapy Guidelines. Steering Group members pointed out significant overlap between this document and Guideline number 15 and it was agreed that these documents should be merged. A large component of the National Guideline document could be used as appendices to existing Guideline 15. Fran, Lucia, Teresa and Sheila will look at the similarities between the two guidelines and attempt to construct a merged document in UK PIN standard guideline format. Richard Herriot indicated he is willing to input as required.</p> <p>There are concerns regarding the confidentiality aspects, utility and incompleteness of the current national UK home therapy registers. Several centres are no longer actively contributing data to these registers. This will be discussed further at the Immunology Forum.</p>	<p>All Steering Grp members</p> <p>O Bryce</p> <p>F Ashworth T Green L Russell S Cochrane</p>
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8. Databases	Action
<p>Bodo Grimbacher gave a demonstration of the ESID Registry database at the PiA in December 2004. Oxford is seeking MREC approval to allow assessment and utilisation of the ESID database. GOS and Newcastle still use their own databases for bone marrow transplantable conditions; these databases should interface with the ESID database in the future. It was noted that the ESID database can be used directly by individual centres who have obtained their own LREC approval without the need to send data to a UK hub, should this be preferred.</p> <p>Carrock Sewell to email Richard Herriot with his September 2004 ESID document which summarises the current status and functionality of the ESID Registry. This will be forwarded to Helen Chapel for comment and updating with any new information and the document will subsequently be sent around all UK PIN members for information.</p>	C Sewell
9. PiA Training Days for Medical Students	Action
<p>It was agreed in discussion at the PiA Medical Advisory Panel meeting in December that the emphasis and concentration of future efforts from the specialty to recruiting trainee Immunologists would optimally have to be at the Foundation Year 2 level rather than on medical students. A single medical student from the PiA-run programme has gone on to become an Immunology SpR. Siraj Misbah has designed an immunology ‘taster’ for an F2 programme operating in Oxford which exposes F2 doctors to Immunology for a two week period. He is happy to send the outline of this short programme to others who may wish to make use of it in their own centre when F2 programmes are being developed/established.</p>	
10. Jeffrey Modell Foundation	Action
<p>There has been no response as yet from immunoglobulin manufacturers to a letter from Richard Herriot requesting sponsorship support for an educational awareness package on PID for primary care and hospital practitioners. Richard Herriot will write again but it is recognised that there are a number of calls being made on finite resource from potential sponsors.</p>	R Herriot
11. UK-PIN Forum	Action
<p>Bobby Gaspar, who chairs the organising committee for this year’s Immunology Forum (18-19 November in York), was invited by the Chairman, at a very late stage, to attend the Steering Group meeting,</p>	

<p>but was unable to attend. The Forum organisers will meet on 3 March 2005.</p> <p>Steering Group items for discussion/presentation at the Forum would be: a) changes to the accreditation standards, b) immunoglobulin registers and home visits, c) further advertising of the availability of PiA-derived monies for consultant and nurse exchange between centres and d) a formal opportunity for Network members to respond/input to the UK PIN constitution. Richard Herriot will update the constitution document for the next Steering Group meeting. Once ratified this will be sent round the membership prior to the Forum. A 45 minute slot at the Forum for 'Steering Group matters' is to be requested.</p> <p>Immunology Forum organisers were asked to liaise with Mike Laycock regarding information about the meeting on the UK-PIN website.</p>	<p>R Herriot</p>
<p>12. World Immunology Day 25 April 2005</p>	<p>Action</p>
<p>Richard Herriot has written to BSI asking if there are any proposed plans/events for World Immunology Day in the UK.</p>	
<p>13. Any Other Business</p>	<p>Action</p>
<p>13a. Pulmonary interest group</p> <p>There was no progress on this issue to report. Richard Herriot indicated he would be prepared to go to Cambridge to discuss taking the matter forward with Kumar and a chest physician who may be interested. David Webster is talking at European Society of Respiratory Medicine later this year on PID and respiratory disease.</p> <p>13b. Steering Group Membership</p> <p>Tim Wallington and Teresa Green formally step down as of today. Sincere thanks were expressed to both for their hard work with the UK PIN Steering Group. David Webster and Alison Jones will step down at the end of calendar year 2005 which means that there will be no London-based representation on the Group. Alison Jones and David Webster were asked to raise this at the next meeting of the pan-London Immunology centres with a request that a name is put forward to sit on the Steering Group. This is consistent with the desire that UK PIN has input from, and represents all, geographical regions in the UK. Andrew Cant attends as Chairman of the PiA Medical Advisory Panel and will demit when the Chairmanship of the panel is passed on. Paediatric Immunologists are asked to consider that this may mean a lack of their representation on the Steering Group and that this may</p>	<p>A Jones D Webster</p>

<p>require some action.</p> <p>13c. Information Leaflets on UK PIN Website</p> <p>Richard Herriot distributed some examples of potentially useful general information leaflets aimed at GPs, Hospital doctors and patients. These examples had been plagiarised from work done by Kumar. Steering Group members were asked to consider whether these sorts of information documents may be usefully posted on the website for centres to adapt and adapt for their own use, in much the same way as guidelines are currently posted. These documents would differ from the Guidelines in that they would not be evidence-based and would not be posted for feedback comment. The purpose would simply be to provide facility for centres to easily download ready-made (or easily adapted) leaflets for their own use. Individual centres could contribute information as or when they saw fit. Similarly, centres could use any of the posted information as or when they needed it. Concern was expressed about duplication with existing PiA information, although some of this is now out of date. The PiA information is also largely aimed at patients whereas the UK PIN site could be a repository for useful information aimed at healthcare staff as well. Richard Herriot would welcome comments.</p>	<p>All Steering Gp. members</p>
<p>14. Next meeting</p>	
<p>To be arranged in late June (Olga to arrange), followed by a breakfast meeting on the first day of Immunology Forum (Cilla to investigate the possibility of a venue).</p>	<p>O Bryce C Freud</p>