

**Minutes of the UK PIN Steering Group Meeting**  
**Held on Monday 11 September 2006**  
**at the Royal Society of Medicine, 1 Wimpole Street, London, W1G 0A**

Present: Richard Herriot - Chairman  
Carrock Sewell - Secretary  
Dinakantha Kumararatne - Treasurer  
Chris Hughan (PiA)  
Fran Ashworth  
Cilla Freud  
Bridget Heelan  
Atholl Munnoch (ZLB Behring)  
Lucia Russell  
Joe Unsworth  
Phil Wood  
Olga Bryce

| <b>1</b>  | <b>Apologies</b>  | <b>Action</b>             |
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|           | Andrew Cant, Terry Flood, Matthew Helbert   |                           |
| <b>2</b>  | <b>Minutes of the previous meeting</b>  |                           |
|           | These were accepted as a true and accurate record, with the exception of item 14.2 which should be amended to read: "Given that 60% of the income from <i>Jeans for Jeans</i> that goes to the PiA goes to research".   | O Bryce                   |
| <b>3</b>  | <b>Matters Arising</b>  |                           |
| <b>3a</b> | <b>ZLB Logo on website and letter head</b><br>Noted that ZLB Behring is to change its name to CSL Behring, links will be made to CSL Behring on the website, and Atholl Munnoch will forward the artwork for the new company logo to Carrock Sewell as soon as it is available. The new CSL Behring logo will appear on both the UKPIN website and the Network's official letterhead. The Steering Group agreed to use the current UK PIN website logo as the Network's logo on both the website and the letterhead. Carrock Sewell will commission new letterheads as soon as the CSL Behring logo is made available | A Munnoch<br><br>C Sewell |
| <b>3b</b> | <b>BSI-CIAS</b><br>Noted that a change to the BSI constitution has been made to incorporate a clinical immunology and allergy society (BSI-CIAS). This was announced in the BSI Newsletter, and is likely to commence in February 2007. The Steering Group noted that UK PIN members voted at <i>Immunology Forum 2005</i> to see what benefits such a society would bring UK PIN members. As any benefits of a UK PIN/BSI link (or indeed a more robust link between the BSI and the Clinical Immunology community in general) are currently unknown;  |                           |

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|          | it was agreed to await formal contact or further information from the BSI-CIAS before taking this matter any further.  |  |
| <b>4</b> | <b>PID Centre Accreditation</b>  |  |
|          | <p>The Steering Group noted that the new documentation for Centre Accreditation is almost complete and that one centre is awaiting accreditation. We agreed that there should be two levels of interaction between PID Centres and UK PIN leading to awarding of Accredited Centre Status:</p> <p><b>Annual Registration of PID Centres with UK PIN (ideally involving/encompassing all UK PID Centres).</b> Registration will involve declaring the number of primary immunodeficiency patients and numbers of immunoglobulin treated patients, which is essential data for estimating the scale of primary immunodeficiency in the UK. Noted that ready access to this data was essential, and agreed that this aggregate data (i.e. consolidated data, no patient-specific information) would be made available on the UK PIN website and would be formally presented at <i>Immunology Forum</i> meetings. This data would be collected on an annual basis. As part of the annual registration process centres would perform a brief self-assessment against a check-list of the new PID Centre Accreditation Standards.</p> <p><b>Formal Accreditation</b> following application, detailed self-assessment, review of self assessment and selected paperwork by the Accreditation Committee, site inspection and correction of any noted deficiencies.</p> <p>Five new documents will soon be available: the updated Standards, Annual Registration Form, Application for Accreditation Form, Guidance notes, and a Protocol for the assessment process.</p> <p>Steering Group members agreed to pilot the registration process when the documents are available</p> <p>The Steering Group agreed to remove the old Standard F9 (on research) as it was a laudable goal, but not a formal standard.</p> <p>Steering Group members were asked to review the new standards and to forward any final comments to Olga Bryce prior to the formal acceptance of the new Standards on 1 October.</p> <p>Richard Herriot is still awaiting formal advice regarding indemnity issues around the accreditation process.</p> | <p>All Steering Group members</p> <p>All Steering Group members</p> <p>R Herriot</p> |
| <b>5</b> | <b>Finance</b>   |  |
|          | <p>Noted that the finances of the Network are £53722.65 in credit thanks to a £40000 donation from ZLB Behring. This has been certified by the accountants at Addenbrookes, where the money is held.</p> <p>Confirmed that the web master is now being paid, despite an earlier hiatus caused by the complexity of NHS accountancy procedures.</p>   |  |

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|           | Agreed that an accreditation fee of £500 per centre (not a registration fee) would be suggested to the Membership for approval at the next <i>Immunology Forum</i> meeting in 2007.  |   |
| <b>6</b>  | <b>Consensus documents</b>   |   |
| <b>6a</b> | <b>Diagnosis and Management of Primary Antibody Deficiencies</b><br>Assessment of the underpinning evidence-base is now complete. This document will be written as a systematic review and submitted for publication to a peer-reviewed journal (possibly <i>Clinical &amp; Experimental Immunology</i> ). From this systematic review, a guideline document will be written for publication by the Royal College of Physicians of London. When finalised it will be put on the website for UKPIN members' comments. Noted that the breadth of material covered does not neatly encompass a single Cochrane Review.  | P Wood  |
| <b>6b</b> | <b>Primary Immunodeficiencies for Managers</b><br>This document is now ready for launching. Agreed that it would be preferable to launch both Consensus Documents simultaneously.  |   |
| <b>7</b>  | <b>Membership</b>  |   |
|           | Current membership is now 176 members  |   |
| <b>8</b>  | <b>Steering Group Membership</b>   |   |
|           | The following changes to the Steering Group were agreed, with some minor changes in terms of office to stagger the change over so as to ensure continuity of Steering Group membership:<br><br>Members demitting office:<br><br><u>2007</u><br>Fran Ashworth; it was agreed to invite the Chair of the RCN Immunology & Allergy Nurses Group, Jackie Moor, as replacement.<br><br><u>2008</u><br>January – Richard Herriot (to initiate voting for new Chair early 2007 with result of voting to be confirmed at <i>Immunology Forum 2007</i> ).<br>December – Carrock Sewell, Cilla Freud<br><br><u>2009</u><br>Lucia Russell (agreed to extend)<br>Phil Wood (agreed to extend)<br><br>David Edgar, as the new Chair of the ACP Immunology Committee to be invited to the Steering Group.<br><br>New Chair of the PiA Medical Advisory Panel to be invited when appointed. | F Ashworth<br><br>R Herriot<br><br>R Herriot<br><br>R Herriot |

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| <b>9</b>  | <b>Guidelines</b>   |                                  |
| 9a        | <b>Home Therapy Guidelines</b> These were accepted and can now move from the 'draft' to the 'current' guideline area on the website (the layout of the complex table still to be edited)  | C Sewell                         |
| 9b        | <b>Constitution of the Guideline Writing Group</b><br>The Steering Group agreed that the guidelines on the website now need updating, as many are now time-expired. Agreed that consideration should be given to future editions of Guidelines adhering to AGREE criteria though this may ultimately prove to be impractical, largely because of available manpower issues. Richard Herriot and Phil Wood agreed to discuss the constitution of the Guideline Writing Group and report to the next Steering Group.  | P Wood &<br>R Herriot            |
| <b>10</b> | <b><i>Immunology Forum 2007</i></b>   |                                  |
|           | Noted that Aarn Huissoon had agreed to chair the <i>Immunology Forum</i> Steering Committee, other members of the group to include: Richard Herriot, Fran Ashworth, Andrew Riordan, Berne Ferry, Lucia Russell and a Trainee (note added: Sujoy Khan). This group will decide the content and location of the meeting, and will canvass the membership for suggestions as to topics for inclusion.  | A Huissoon                       |
| <b>11</b> | <b>AAAAI Survey</b>   |                                  |
|           | Noted a request from ESID for UKPIN members to respond to the AAAAI survey on primary immunodeficiencies, which should be completed by 20/9/2006  | All Steering<br>Group<br>members |
| <b>12</b> | <b>Immunoglobulin Supply</b>  |                                  |
|           | <p>The Steering Group received an update on the discussions with Deloitte and the DoH regarding the current UK IVIg shortage. UK PIN has given a written response in a document co-authored with the ACP, PiA, and LUCIT. A report from Deloitte has apparently been made to the DoH with recommendations, but these have not yet been made public. We noted that the following are likely to be incorporated within the Deloitte recommendations (on the basis of meetings held):</p> <ul style="list-style-type: none"> <li>• Formation of a long-term central group to oversee the implementation of the Deloitte recommendations</li> <li>• This group to produce guidelines for rational IVIg use and to coordinate appropriate studies, as well as to ensure good communications between IVIg prescribers and the DoH.</li> <li>• The formation of regional IVIg 'oversight' groups and a national IVIg register</li> <li>• Improved links between pharmacies and clinicians for planning IVIg requirements in individual trusts.</li> <li>• UK price control is unlikely to be beneficial</li> </ul> <p>Also noted, with regret, that the DoH had refused to discuss the</p> |                                  |

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|           | current situation of UK plasma fractionators or the UK as a source of plasma, despite all the UK PIN members present at the discussions insisting that appropriate strategic solutions would not be found without considering these issues. Also noted that there were no current plans from the DoH to look at the IVIg situation from a UK-wide perspective.  |           |
| <b>13</b> | <b>WHO Essential Medicines List</b>   |           |
|           | Agreed to support the inclusion of therapeutic immunoglobulin on the WHO List of Essential Medicines. Current efforts to have immunoglobulin products reinstated on the WHO list are being coordinated by IUIS and IPOPI. Because of the short timescale for completion of applications in the current round, Richard Herriot has taken Chairman's action and given formal support from UK PIN to these bodies in their efforts with the WHO, via a designated list of supporting organisations. Richard Herriot will circulate final document submitted to the WHO when available.   | R Herriot |
| <b>14</b> | <b>EU Consensus on Primary Immunodeficiencies</b>   |           |
|           | Noted the reports of this meeting held recently in Frankfurt, which has led to the production of consensus recommendations regarding awareness & education, screening and diagnosis, and management of these conditions. These will be presented at ESID, and are for eventual EU-wide distribution to GPs, schools, etc.   |           |
| <b>15</b> | <b>Nurse roles in UK PIN</b>  |           |
|           | The role of nurse-nurse dissemination of information about possible Immunoglobulin reactions was discussed. Agreed that that the existing, formal, recommended 'Yellow Card' method of alerting clinicians to possible reactions should be followed, but that it is also important and appropriate that possible problems are discussed directly with the relevant manufacturer. In addition, we agreed that messages should be sent to the UK PIN Steering Group, rather than general emails to all nurses, so that a coordinated response could be produced if required. We also agreed to have a standing item on 'Immunoglobulin Problems' on the Steering Group agenda.  | O Bryce   |
| <b>16</b> | <b>Links with CSL Behring</b>   |           |
|           | Noted and confirmed, under the terms of the agreement between UK PIN and ZLB/CSL Behring, that CSL Behring may utilise Steering Group members as an Advisory Panel for discussion of issues such as product development, clinical trial design and clinical queries. Steering Group members were reminded that the activities of, and opinions expressed within the context of the Advisory Panel are distinct from those of the UKPIN Steering Group. The functions, and responsibilities of the UK PIN Steering Group and the CSL Behring Advisory Panel are therefore formally and definably separate. Members were advised of the recommendation that membership of any such Advisory Panel should be declared in relevant individual 'declarations of interest'. |           |

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| <b>17</b> | <b>Any Other Business</b>   |  |
| 17a       | <b>XLPS Research Trust</b> – a link to this group has been made on the UK PIN website. Noted that it was unusual for an immunodeficiency-associated charity to be separate from the PiA, but were reassured that the Trust works closely with the PiA.  |  |
| 17b       | <b>Discovery Channel Programme on CVID</b> – noted that Carrock Sewell has been approached by Firefly Productions who intend to make a programme on CVID for Discovery Channel. Interested members should make themselves known to Carrock.   |  |
| 17c       | <b>Erroneous glucose readings with certain IVIg preparations</b> – Kumar advised the Steering Group members that a situation had arisen with erroneous finger prick blood glucose readings occurring in a patient receiving disaccharide-containing IVIg. Carrock Sewell offered to produce an item on this for <i>Immunotherapeutics Quarterly</i> . | C Sewell,<br>Kumar                     |
| 17d       | <b>IVIg dose in obese patients</b> – Kumar noted that the g/kg body weight calculations for obese patients should perhaps be based on ideal body weight rather than actual body weight, as this makes a significant difference to IVIG dose required.   | All Steering Group members to consider |
| 17e       | <b>IVIg for Bone Marrow Transplantation</b> – Kumar offered to distribute guidelines recommending that IVIg is no longer essential during bone marrow transplantation.  | Kumar                                  |
| 17f       | <b>PiA Children’s Activity Holidays</b> – noted that volunteers are required for the Keswick and canal boat activity holidays run by the PiA.   | All Steering Group members             |
| <b>18</b> | <b>Date and time of next meeting</b>  |  |
|           | Olga Bryce will circulate possible dates for the next Steering Group Meeting in November.   | O Bryce                                |