

MINUTES OF UK PIN STEERING GROUP MEETING
held on Thursday 27 September 2007
at the Royal Victoria Infirmary, Newcastle upon Tyne

Present: Richard Herriot
Carrock Sewell
David Edgar
Terry Flood
Bodo Grimbacher
Matthew Helbert
Phil Wood
Lucia Russell
Fran Ashworth
Olga Bryce

1.	Apologies	Action
	Jackie Moor, Chris Hughan, Kumar, Carl Wheeler, Joe Unsworth.	
2.	Minutes of the Previous Meeting	
	The minutes of the meeting held on 16 April 2007 were accepted as a true and accurate record.	
3	Matters Arising	
3a	<p><i>Consensus Documents</i></p> <p>(i) Phil Wood and colleagues were congratulated on their publication of the systematic review of the evidence base for recognition, clinical diagnosis and management of antibody deficiencies in this month's <i>Clinical & Experimental Immunology</i>.</p> <p>(ii) Construction of an RCP Short Guideline on antibody deficiency is being undertaken by a working group led by Phil Wood. It is planned that the Guideline will be completed by Easter 2008.</p> <p>(iii) Document on antibody deficiency for managers is largely complete. Discussions will be had with the PiA as to whether they would support publication as a stand-alone document, or help fund reprints if published in the <i>Health Services Journal</i> or journal of the British Association of Medical Managers.</p>	R Herriot
3b	<p>Nursing input into the Guideline Writing Group</p> <p>No volunteers emerged from the recent RCN meeting. Ruth Weldon to be asked to circulate a further call for volunteers. Fran Ashworth volunteered to continue to help with the Guideline Writing Group once she leaves the Steering Group.</p>	L Russell

3c	<p><i>Influenza Pandemic Planning</i></p> <p>Richard Herriot is writing this document with a PID emphasis at the request of Bill Egner who has been tasked by the RCP to develop specialty strategic plans for coping in the event of a future pandemic. Early discussions with Virologists and pharmacies have indicated that it is unlikely that antiviral agents will be available for prophylactic use in PID patients on any kind of routine or widespread basis.</p>	R Herriot
3d	<p><i>STEP Subcutaneous Immunoglobulin Therapy</i></p> <p>Copies of this educational programme are available from CSL Behring for any UK PIN centres who have not already received one.</p>	All
4.	Financial Position	
	Current position is £34,769 in credit.	
5.	UK PIN Constitution	
	Updated version to be circulated to membership after this meeting. Major change is page 4, providing for formal affiliation with other organisations if required. Steering Group accepted this document and it will now be circulated. Olga to circulate new constitution – but correct the 2005 renewal date to 2009.	O Bryce
6.	UK PIN Membership	
	193 current members, with continued growth.	
7.	UK PIN Website	
	<p>The Website has been considerably refreshed and updated.</p> <p>ESID Guidelines for the investigation of suspected immunodeficiencies have been web-enabled and are ready to appear as an application on the UKPIN website. Once finalised, the Steering Group will examine the application on-line for approval. Mike Laycock was thanked for his input in designing this application. Carrock Sewell and Richard Herriot to discuss mechanisms of launching this application, which fits well with the rest of the portfolio of services UKPIN are developing (Consensus Guidelines etc).</p>	<p>C Sewell M Laycock</p> <p>C Sewell R Herriot</p>
8.	Steering Group Membership	
	Nursing representative – Jackie Moor will take over from Fran Ashworth at the first Steering Group meeting held in 2008.	

	<p>Chairmanship – following a process of consultation with all UK PIN members, Phil Wood has volunteered to be the next Chair of UK PIN and this application was welcomed and approved by the Steering Group. This will be announced at the Immunology Forum.</p> <p>Matthew Helbert was thanked for extending his stay on the Steering Group.</p>	
9.	UK PIN Centre Registration	
	<p>Current status: 18 Centres have completed and sent in registration forms, from a total of approximately 30 Immunology units. Aggregate data from this registration process to be presented at Immunology Forum.</p>	J Unsworth
10.	UK PIN Centre Accreditation	
	<p>One outstanding assessment by Helen Chapel and Fran Ashworth visit (Hope Hospital, Salford) is scheduled for early December. Cardiff has expressed an interest in being assessed by has not formally submitted an application – Olga Bryce to chase up. The Royal Brompton may be interested in assessment but has not yet formally applied. Joe Unsworth and Richard Herriot to discuss.</p>	<p>O Bryce</p> <p>J Unsworth</p> <p>R Herriot</p>
11.	Immunoglobulin Supply	
	<p>The DH strategy for addressing the immunoglobulin supply was discussed, following the June meeting at RCP. A draft patient information leaflet from Deloitte has been seen by Richard Herriot and others and there was general agreement that UK PIN, the PiA and the RCPCH have all found the leaflet to be confusing for patients. These bodies have submitted suggestions for how to improve the leaflet. The national guidelines on acceptable uses for immunoglobulin therapy have yet to be published, and concern was expressed over the status of specific polysaccharide antibody deficiency in the draft guidelines. Carrock Sewell outlined the proposals for the National Immunoglobulin Database, which will register all immunoglobulin use. Concerns were raised about the mechanisms of data entry, particularly in peripheral hospitals where IVIg is prescribed by a specialist centre but administered locally. The NID will undergo extensive pilot testing, to ensure these issues are addressed prior to national use. Carrock Sewell will be presenting the NID at Immunology Forum so UK PIN members will see what sort of information will be recorded. It was noted that additional help may be available from the DH to assist with data input.</p> <p>Carl Wheeler reported (via Richard Herriot) that manufacturers with immunoglobulin supply problems have to report to PASA who will try to coordinate alternatives; the mechanism of this assistance remains unclear.</p>	

	Helen Chapel (via Richard Herriot) thanked all UK PIN members for their helpful input into supporting the bid for SCIG to be placed on the WHO List of Essential Medicines. Promising discussions were held in July in Geneva, and the outcome will be announced in October.	
12.	UK PIN/BSI Immunology Forum	
	The Immunology nurses were congratulated on developing an excellent parallel session for the Immunology Forum. The Steering Group approved the programme for this meeting. The meeting is now fully subscribed; there is a waiting list for those still hoping to attend. Start and finish times have been changed slightly.	
13.	UK PIN Registry	
	Seven responses were received by Richard Herriot in response to the Registry Proposal document circulated to the membership on 10/9/07. Issues raised centred mainly on the practical aspects of data entry, ownership of data and flexibility of the Registry for clinical care and research purposes. The responses were all read and discussed by the Steering Group. There is general acceptance that a Registry of some sort is required and desirable. All Steering Group members present undertook to support and promulgate the development of a UK PID registry linked to the ESID database, based on governance from UK PIN. This model allows for flexibility in designing UK fields without recourse to ESID but it is important to construct a system which will not require centres who have already entered patients into the ESID database to have to go through a process of re-consenting patients or obtaining new, detailed ethics approval. These issues will be discussed further at the Registry breakout session during the Immunology Forum. There will be a need to develop a Registry Committee within UK PIN. Ongoing, substantive administrative assistance with data entry was seen as essential to the success of this project. Consent and ethics approval issues were also seen as critical, but can be facilitated by central and on-site input from Viviane Knerr. Bodo and Viviane will proactively look into the need for re-consenting patients already entered into the ESID Registry.	B Grimbacher
14.	AOCB	
	Centre for Immunoglobulin Therapy Centre website nearly ready for launch (www.immunoglobulin-therapy.org), experts being recruited. The Steering Group agreed that having a page showing the latest product availability status for all products, would be very much welcomed.	
	Prion Study A fourth case of prion infection from blood components	

	<p>occurred in 2007. Matthew Helbert reported two further incidents of gastroenterologists mistakenly believing that endoscopy cannot be undertaken on antibody deficient patients. Ethical approval for the Prion Study is progressing in several UK Centres with patients who meet the recruitment criteria. 25 patients have been recruited to date and so far 14 tissue samples (all negative) obtained.</p>	
	<p>BSI-CIAS</p> <p>Progress in formation of this new section of the BSI has been relatively slow from the external perspective but there is significant ongoing activity and background discussion between BSI and the Clinical Immunology community. The BSI readily see the advantages of a robust relationship with the clinical community and are beginning to assimilate the needs of the clinical community in making the relationship beneficial for both parties. The Steering Group agreed that UK PIN has core aims and objectives which are definably separate from those of the BSI-CIAS and that therefore UK PIN should continue to exist in its own right. UK PIN input into the BSI-CIAS executive committee is required, and it was agreed that effective and informed representation should optimally come from one of the Steering Group Officers (i.e. the Chair, or Secretary or Treasurer as a deputy) rather than from identifying representation through a vote of UK PIN members.</p> <p>ACP links</p> <p>Agreed that David Edgar will ask ACP Council if they still see benefit in, and wish to act as a host for UK PIN. At present, no active, formal support from the ACP is received (or sought) for UK PIN activities. Previous requests for re-clarification of the relationship between the ACP and UK PIN have had no clear outcome.</p>	D Edgar
15.	Date and Time of Next Meeting	
	<p>Manchester Royal Infirmary/Manchester Airport - end of January beginning of February 2008. Olga to circulate dates.</p>	O Bryce