

**MINUTES OF UK PIN STEERING GROUP MEETING**  
**held on Monday 12 May 2008**  
**at the Royal Society of Medicine, London**

Present: Phil Wood – Chair  
 Carrock Sewell - Secretary  
 Dinakantha Kumararatne – Treasurer  
 Chris Hughan - PiA  
 David Edgar  
 Bodo Grimbacher  
 Aarn Huissoon  
 Lucia Russell  
 Carl Wheeler  
 Olga Bryce

1.	<b>Apologies</b>	<b>Action</b>
	Jackie Moore, Matthew Helbert, Cathy Cale, Terry Flood, Joe Unsworth	
2.	<b>Minutes of the Previous Meeting</b>	
	The minutes of the meeting held on 31 January 2008 were accepted as a true and accurate record, with the exception that David Edgar was not present. Olga will send the amended minutes to the webmaster for uploading to the website.	O Bryce
3	<b>Matters Arising</b>	
3a	<p><b><i>Consensus Documents</i></b></p> <p>Chris Hughan has produced an initial design and the PiA now just need the final amendments and then can go into production. He will ask all Centres how many copies they need. Production is likely by mid-June. Foreword from UKPIN to be written by Phil Wood.</p>	C Hughan P Wood
3b	<p><b><i>Pandemic influenza guidelines</i></b></p> <p>Final document still to be approved by Steering Group – Carrock Sewell will circulate this, then put the final document in the Guidelines section of the website.</p>	C Sewell
4.	<b>Financial Position</b>	
	<p>The previous increase in expenditure was for the administrative assistant's salary. Financial Year 2007/8 expenditure was £21,568 and current balance is £19,276.61.</p> <p>Carl Wheeler reported that CSL Behring has kindly agreed further funding for FY 08/09 and 09/10.</p> <p>The Steering Group discussed travel expense policies and committee members agreed to economise wherever possible, but declined to produce a formal policy.</p>	

<b>5.</b>	<b>UKPIN Membership</b>	
	<p>Membership now stands at 200 with new members and retiring members. Olga will check the current membership list against the <i>Immunology Forum</i> attendees and ensure that all possible members have been asked to join. We will plan for a repeat check of the membership data in February 2009.</p> <p>We agreed that pharmacists also welcome to join UKPIN, particularly as more pharmacists will be involved with IVIG with the DH Demand Management Plan. Agreed: to invite immunology pharmacists to join if interested.</p>	<p>O Bryce</p> <p>P Wood</p>
<b>6.</b>	<b>UKPIN Website</b>	
	<p>M Laycock still not paid for web-enabling diagnostic website –Bodo Grimbacher asked that the time spent on the site by the webmaster be recorded. Phil Wood was briefed on this issue (not present at this stage of meeting) and felt that current arrangements were entirely satisfactory. Olga will chase up the invoice, and ask Mike to log the time spent on UKPIN work.</p>	<p>O Bryce</p> <p>M Laycock</p>
<b>7.</b>	<b>UKPIN PID Centre Registration &amp; Accreditation</b>	
	<p>The Accreditation Committee met on 28 April and remains concerned about the slow uptake of both registration and accreditation. Centres which have not yet registered will be sent a reminder/invitation. An ESID poster of Registered Centre data will be produced. The existing registration data has been studied to identify reasons for failure of centres to register. Identified causes are: staffing, accommodation and the effort required to produce documentation. The Standards will be reviewed to see if these are putting Centres off applying for registration or accreditation. Steering Group members supported these moves, particularly re-examining the standards to see how non-achievable standards could be re-written. The Accreditation Committee had concerns about Centres being 'graded' in case 'lower scoring' centres were disadvantaged in terms of Choose &amp; Book/Commissioning. The PiA voiced concern that this issue is not progressing. Single-handed Centres were encouraged to network in order to provide creditable levels of support. Kumar asked that the standards could include information about minimum standards of cover. It was agreed that a list of registered and accredited centres, along with numbers of cases seen, would help exert peer pressure to register.</p> <p>The Group agreed that this year the main effort would be to get all centres to at least register, and to focus on re-writing standards that are impeding this process. Standards and advice which would encourage mutual support between single-handed centres should be encouraged. The Steering Group agreed to only accept existing applicants for accreditation over the next year. Any inspections in the next 12 months would be against existing standards.</p> <p>Olga and Carrock will look at the Re-Registration form for 2008 to ensure that Centres receive their previous data and can simply amend data that has changed.</p>	<p>O Bryce</p> <p>C Sewell</p>

<b>8.</b>	<b>DoH Guidelines and Demand Management Plan</b>	
	<p>The Department of Health Immunoglobulin Demand Management Plan and proposed clinical indication colour-coding system was discussed. Carl expressed concern that reduced immunoglobulin use in the UK may make UK a less-attractive market. The group agreed that immunologists must be involved with their SHA level panels – Phil Wood will write to SHA chairs to request this. SHAs appear to be wanting to commission for 2009-10.</p> <p>The Committee heard that (GS1 standard) bar-coding of immunoglobulin products will be required in the future, and this will facilitate data entry into the national immunoglobulin database.</p>	P Wood
<b>9.</b>	<b>UKPIN PID Registry Committee</b>	
	<p>Terms of reference for the UKPIN Registry Committee were discussed. Legal issues of liability and data protection have been examined and a draft agreement is being produced, but costs for a legal opinion regarding liability protection have been requested. David Edgar will obtain an estimate of these costs before Steering Group considers approving payment for this advice. A UKPIN Officer will be listed on the MREC. The Registry Committee members will be Vivianne, Bodo Grimbacher, Hilary Longhurst (on behalf of the PiA), three nursing representatives, Tony Williams and David Edgar. The Group approved Chris Hughan attending as an observer. The Committee will meet in late June. The Steering Group approved the eight terms of reference (appended to these minutes). The legal title is: 'The UK Version of the ESID Database'. The Steering Group approved the name 'UK Primary Immunodeficiency Registry'. It was noted that the UKPIN Steering Group is the body that will decide what the data is used for and who can access it.</p> <p>In order to reinforce the need for centres to be Registered Centres, it was agreed that only Registered Centres would be able to enter data onto the UK Primary Immunodeficiency Registry. This policy will be kept under review.</p> <p>David Edgar will discuss the Registry at the PiA AGM, and at EAACI, and aims to do a poster for ESID.</p>	D Edgar
<b>10.</b>	<b>Guideline Writing Group</b>	
	<p>The Group agreed to put the two draft Standards of Care documents on the website for comments.</p> <p>It was agreed that the Standards should be explicitly listed in the documents so that they can be audited within each centre.</p> <p>Distinction was to be made between Standards of Care (which can be listed, and should be short documents), and a 'quality manual' of procedures and protocols which many centres find tedious to produce. The <i>Compendium of Immunology</i> used by the Trent Regional Immunology &amp; Allergy Consortium was discussed as being a model that centres can freely download,</p>	O Bryce C Sewell

	and UKPIN may eventually offer a similar document for centres to copy and modify as required without having to produce their own from first principles.	
<b>11.</b>	<b>Review of Business Plan 2006-2010</b>	
	This document was discussed. Page 4 strategic objectives in the draft version were written on the assumption that accreditation would become a self-funding process and it is clear that this is unlikely at present. These objectives will therefore be re-written, and will include aspirational aims such as enhancing communication with national bodies. The re-written document will be emailed to the Steering Group for further input.	P Wood
<b>12.</b>	<b>Constitution for discussion</b>	
	This document has been updated to incorporate a Registry Committee (page 5) and was approved by the Steering Committee. The 2008 constitution will be put on the website and will be ratified at the next Immunology Forum.	O Bryce M Laycock
<b>13.</b>	<b>Immunology Forum 2009</b>	
	Mark Gompels has agreed to chair the organising committee for <i>Immunology Forum 2009</i> . The location has not yet been decided, as more attendees are expected but larger venues will incur a greater cost. The tender for the organising company should include estimates for different sizes of meeting. It was agreed that a representative from the commercial supporting companies should also be on the organising committee, and PATA would be asked to suggest someone; Carl will discuss this with them and produce a name. A joint meeting with BSI-CIAS was discussed and the Steering Group opted for independent meetings. Steering Group opted for a more formal handover of Steering Group officers at <i>Immunology Forum</i> . Agreed that the meeting could also be used to recognise the success (individual or group) of various centres, suggestions for suitable award categories to Carrock Sewell.	C Wheeler  M Gompels C Sewell
<b>14.</b>	<b>Executive Officers – formal changeover and election</b>	
	Carrock demits as secretary in July 2008 – Phil Wood will email the membership asking for expressions of interest in this post.	P Wood
<b>15.</b>	<b>Early and Appropriate Diagnosis Campaign 2008 (Oyster/BPL)</b>	
	Oyster and BPL's campaign to raise awareness for early diagnosis of primary immunodeficiency was discussed. The Steering Group considered the proposals and agreed to support the objectives. Aarn Huissoon and Kumar offered to join the Advisory Group for this as UKPIN Representatives.	
<b>16.</b>	<b>Audit of IVIG Practice</b>	
	An audit proforma for a UKPIN-wide audit of IVIG prescribing standards was circulated and approved. This will be placed on website and invitations to participate will be in the chairman's newsletters.	C Sewell P Wood

<b>17.</b>	<b>Any Other Business</b>	
	<p><b>Prescription charges</b> the PiA continues to receive requests from members about campaigning for free prescriptions for PID patients and wondered about the UKPIN stance on this. The Steering Group offered to write to the relevant authorities with a joint letter of support to be written with the PiA</p>	P Wood
	<p><b>UKPIN email newsletter</b> Phil Wood agreed to produce a newsletter from the UKPIN Chair every three months</p>	P Wood
	<p>UKPIN is now on the official register of UK Health-related organisations</p>	
	<p>NICE have invited comments from UKPIN about being sent lists of drugs for appraisal. We will undertake this and will invite NICE to look at immunoglobulin.</p>	P Wood
	<p>Steering Group members were invited, as part of their remit following CSL sponsorship of UKPIN, to participate in a 2 hour meeting as an Advisory Board for CSL following the next Steering Group meeting.</p>	All Steering Group members
	<p>The new PiA info leaflets were distributed by Chris Hughan and more copies are available from the PiA.</p>	
<b>18.</b>	<b>Date of Next Meeting</b>	
	<p>Confirmed as 15<sup>th</sup> September 2008, London.</p>	