

MINUTES OF UK PIN STEERING GROUP MEETING
held on Monday 15 September 2008
at the Royal Society of Medicine, London

Present:

Cathy Cale, Bodo Grimbacher, Chris Hughan, Kumar (Treasurer), Lucia Russell, Carrock Sewell (Secretary), Joe Unsworth, Carl Wheeler, Phil Wood (Chair)

1.	Apologies	Action
	Olga Bryce, Aarn Huissoon Jackie Moore, Matthew Helbert, Terry Flood, David Edgar	
2.	Minutes of the Previous Meeting	
	The minutes of the meeting held on 12 May 2008 were accepted as a true and accurate record, with the exceptions of the spelling of 'foreword' in item 3a, and PPTA in item 13. Olga will send the amended May minutes to the webmaster for uploading to the website.	O Bryce
3	Matters Arising	
3a	<p><i>Consensus Documents</i></p> <p>The PiA is in the final stages of choosing illustrations for the Consensus Document, which is likely to be ready for production by the end of October. Financial support, of around £5000, is still required.</p>	C Hughan
3b	<p><i>Pandemic influenza guidelines</i></p> <p>The final document still to be approved by Steering Group – Carrock Sewell will circulate this, then put the final document on the Guidelines section of the website.</p>	C Sewell M Laycock
4.	Financial Position	
	<p>The current balance is £19 276.61</p> <p>It was agreed that the Steering Group should ensure, following Agenda for Change implementation, that the Administrative Assistant's Job Description is current, workload is appropriate, and that appropriate appraisal systems are in place. The Secretary will check this with Gavin Spickett and Olga Bryce.</p>	C Sewell
5.	UKPIN Membership	
	<p>Membership now stands at 205. The Secretary and the Admin Assistant will check through the membership database to see if there are unregistered immunologists/nurses who could be encouraged to join.</p> <p>Chris Hughan kindly agreed to write a UKPIN update for <i>Insight</i></p>	O Bryce C Sewell C Hughan
6.	UKPIN Website	
	It was agreed that some elements of the website were now out	M Laycock

	of date, and the Secretary and the Webmaster should now review all pages to ensure that it is up-to-date. It was noted that Mike Laycock is away throughout September, so changes to the website will not be possible then.	C Sewell
7.	UKPIN PID Centre Registration & Accreditation	
	<p>The Accreditation Process is currently suspended whilst a push is made to get as many UK Centres as possible to become Registered Centres. Plymouth and Sheffield are currently accredited; the accreditation status of other Centres has either expired or were pilot-phase accreditations.</p> <p>At the last meeting of the Accreditation Committee in April 2008, all the standards were reviewed and are now being updated where necessary. Once this is complete, the Accreditation Committee Chair will circulate the revised standards to the Steering Group.</p> <p>The Steering Group agreed that Centres should be able to accredit as either a Paediatric Immunology Centre, or as an Adult Immunology Centre that also sees children. It was also agreed that single-handed practice is not ideal, but is likely to remain an issue in some areas, so networking with peer-review and audit should be strongly encouraged.</p> <p>There are now 25 registered centres, but this falls short of the total number of known immunology departments. The website will therefore include a list of UK cities, highlighting those with Registered Centres. Jo Unsworth to send C Sewell a list of centres currently registered.</p> <p>It was agreed that it would be helpful to have a research nurse to assist centres collect their registration data, and to identify patients for subsequent UKPIN Registry entry. The Chair will examine mechanisms of funding such a post, and the Secretary and Chair to discuss a job description and practicalities of such a post.</p> <p>The Secretary and the Administrative Assistant will produce an easy-to-complete spreadsheet for each registered Centre, containing last years data, with a column for any changes, and will circulate these to each centre for this year's update.</p>	<p>J Unsworth</p> <p>C Sewell M Laycock J Unsworth</p> <p>P Wood C Sewell</p> <p>O Bryce C Sewell</p>
8.	DH Guidelines and Demand Management Plan	
	The Chair reported that he had now written to the CEO of all Trusts emphasising UKPIN's concerns that an immunologist should be a member of each SHA level panel; 50% had responded and most agreed that this would be appropriate (if they had an immunologist).	
9.	UKPIN PID Registry Committee	
	<p>No report has been received yet detailing estimates of a cost for obtaining a legal opinion regarding liability protection have been requested.</p> <p>Discussions are still underway between the Royal Free Hospital</p>	D Edgar

	<p>and UCL regarding who will be the responsible authority for maintaining the database.</p> <p>MREC approval has been given for the UK version of the ESID Database. Over 900 UK patients have now been registered, making the UK the third largest contributor to the ESID Registry (after France, then Turkey). Reporting tools are now available to be able to examine the Database on an individual patient basis. Bodo Grimbacher and Vivienne will produce a step-by-step guide for UK Database users.</p>	B Grimbacher
10.	Guideline Writing Group	
	<p>Standards of Care (SoC) documents will gradually replace the current Guidelines; these documents will be semi-didactic, and will contain a summary of the (max) 10 key standards that should be incorporated into locally-produced guidelines. Such guidance will be practical, rather than aspirational. The first two draft Standards of Care will be emailed around the Steering Group for comments, before the final version is put on the website. It was agreed that: as the SoC documents undergo a thorough production process, the Standards of Care documents will not go out to the entire UKPIN membership for approval before being published. Instead, the GWG will notify the Secretary & Webmaster once a new SoC has been agreed by the GWG and is ready for publication. The UKPIN website can (and does) link to locally produced guidelines, such as the TRIAC <i>Compendium of Immunology</i> which Centres may wish to use as templates for their own guidelines/quality manuals.</p>	<p>O Bryce C Sewell</p> <p>C Cale</p>
11.	Review of Business Plan 2006-2010	
	<p>The re-written Business Plan was discussed. The aims and objectives were agreed, with minor changes being (1) change obtainable to attainable on page 3, and (2) change newsletter to email newsletter on page 4, and (3) closing balance should be £19277 on page 6.</p> <p>It was stressed that no formal merger with BSI-CIAS (page 7) is being proposed. The benefits of closer working between the two bodies remain to be established, although it was acknowledged that working together for joint meetings is a useful strategy.</p> <p>Further plans for increasing the financial viability of UKPIN were briefly discussed, with the agreement that the Chair, Secretary and Treasurer would produce an option appraisal for the next meeting.</p>	<p>P Wood C Sewell Kumar</p>
12.	Surveys	
	<p>UKPIN receives numerous requests for distribution of surveys and questionnaires. In order to reduce the email burden of UKPIN members, and yet facilitate putting UKPIN members in touch with relevant research groups, it was agreed that the Chair will include a selection of URL links to the researchers' websites for inclusion in the biannual email newsletter. Email addresses of UKPIN members would not be released to third parties.</p>	P Wood
13.	Immunology Forum 2009	

	The next meeting of <i>Immunology Forum</i> will be held in November 2009. An organising committee has been assembled by Mark Gompels. The PPTA are selecting a representative to sit on this committee. The Steering Group has already recommended that <i>Immunology Forum</i> would be a suitable setting for announcing the change-over of UKPIN officers, and for any awards or prizes that UKPIN may wish to announce.	M Gompels
14.	Executive Officers – formal changeover and election	
	Carrock Sewell agreed to stay on as UKPIN Secretary until January 2009 when Fran Ashworth and Lucia Russell will take over as joint Secretaries.	
15.	Informatics Lead	
	Following nomination by Lucia Russell and Cathy Cale, Carrock Sewell agreed to remain on the Steering Group with the new role of Informatics Lead. This post will include responsibility for: overall responsibility for the UKPIN website; liaising with UKPIN committees regarding data collection and organisation; supporting the Secretaries in maintaining central records; liaising with external bodies (including the PiA) regarding access to UKPIN data via the Steering Group. The Informatics Lead will be accountable to the Steering Group through the provision of reports, and will be an <i>ex officio</i> member of the Steering Group.	
16.	Audit of IVIG Practice	
	Following an initial pilot kindly undertaken by the Royal Free Hospital, the UKPIN audit of IVIG practice will now be circulated to all UK Centres by inclusion of a link in the email newsletter and with a page on the UKPIN website.	C Sewell M Laycock P Wood
17.	Any Other Business	
	Centre for Immunoglobulin Therapy is now operational, with a website at www.immunoglobulin-therapy.org This virtual centre addresses all aspects of immunoglobulin therapy, and includes an availability page describing the current supply of immunoglobulin products in the UK. Laboratory result reporting A UKPIN Member is seeking the view of UKPIN regarding the appropriateness of certain comments on laboratory reports. This was not felt to be a UKPIN issue; the Chair will write to the Member expressing this view.	P Wood
18.	Date of Next Meeting	
	Dates to be circulated.	O Bryce