

MINUTES OF UK PIN STEERING GROUP MEETING
held on Thursday 31 January 2008
at the Manchester Royal Infirmary, Manchester

Present: Richard Herriot
Carrock Sewell
David Edgar
Kumar
Bodo Grimbacher
Matthew Helbert
Phil Wood
Fran Ashworth
Olga Bryce
Carl Wheeler
Chris Hughan
Jackie Moor

1.	Apologies	Action
	Terry Flood, Lucia Russell, Joe Unsworth.	
2.	Minutes of the Previous Meeting	
	The minutes of the meeting held on 27 September 2007 were accepted as a true and accurate record.	
3	Matters Arising	
3a	<p><i>Consensus Documents</i></p> <p>The Document 'Primary Immunodeficiencies: an introduction for managers' is complete and a quote is being developed by the PiA for printing this document. Chris Hughan will contact all centres asking for anticipated numbers of copies needed. Matthew Helbert and Chris Hughan will discuss ways of publicising the document using the PiA's public relations company.</p>	C Hughan M Helbert
3b	<p><i>Nursing input into the Guideline Writing Group</i></p> <p>Several nurses have kindly volunteered to participate in the Guideline Writing Group. The Steering Group considered a proposal for a short-life re-issue of the existing Guidelines for a limited period, prior to the development of Standards of Care later in the year. There was some discussion about the potential benefits and disadvantages of doing this with no agreed consensus. Note added following meeting: the GWG will now <i>not</i> be re-issuing the Guidelines, but will instead proceed directly to producing Standards of Care, and accept that some Guidelines will remain out of date until SoC are developed.</p>	
3c	<p><i>MHRA Database of health-related NGOs</i></p> <p>The Steering Group approved the proposal for entering UK PIN onto the MHRA database as a health-related NGO. This may have potential advantage in allowing rapid communication of MHRA concerns about relevant medicines or devices to the</p>	

	Network.	
3d	<p>Constitution</p> <p>The Steering Group noted the ratification of the latest edition of the UK PIN Constitution at the Immunology Forum 2007, and that it is now available on the website.</p>	
4.	Financial Position	
	<p>Noted that the September 2007 statement showed a balance of £34,700 with the January 2008 balance at £24,237.07, suggesting that there has been substantial additional spend in the interim. The reasons for this increase in expenditure are not clear so will be investigated by Kumar. It was noted that the Addenbrookes Hospital Finance Department automatically audits the UK PIN accounts, which it hosts, which is significantly beneficial to the financial governance of the Network. Noted also that late or delayed notification of invoices to be paid causes operational problems for the Finance Department at Addenbrookes and that all invoices should be sent to the UK PIN Office and thence forwarded to Cambridge as expeditiously as possible.</p> <p>Problems were reported with the website invoices for domain registration and server space. This was due to outdated contact information being held by the internet service provider; Olga's contact details have now been provided so that invoices can be dealt with efficiently and maximum notice can be given to the Finance Department.</p> <p>The Steering Group voted to allow 23p/mile for car travel claims.</p> <p>It was noted that the meeting to discuss the feedback and outcomes of <i>Immunology Forum 2007</i> will be held next week, and that finances for the meeting are held in a separate account to general UK PIN funds. Any surplus should be carried forward to the next meeting.</p> <p>Carl Wheeler noted that UK PIN sponsorship is seen by CSL Behring as an important part of maintaining links with the Immunology community, and asked that they be kept informed about predicted expenditure well ahead of time, to enable planning for any future continuation of sponsorship funding.</p>	<p>Kumar</p> <p>O Bryce</p>
5.	UKPIN Membership	
	<p>Membership now stands at 200 members. The membership database continues to be maintained by Olga, who will email all members to ensure that their contact details are correct.</p>	O Bryce
6.	UKPIN Website	
	<p>Noted that the site was unavailable for one week in December whilst the internet hosting server changed ownership.</p> <p>Carrock Sewell and Mike Laycock were congratulated and thanked for their work in developing the web-based diagnostic</p>	

	tool based on the ESID guidelines.	
7.	UKPIN PID Centre Registration	
	21 Centres now registered. Re-registration will be needed on an annual basis. All Centres are to be reminded around Easter to re-register (i.e. update their data). Olga will send out the original registration forms for Centres to update to reduce the need for Centres to supply basic information already submitted at initial registration (addresses, contact details etc.).	O Bryce
8.	UKPIN Centre Accreditation	
	<p>Salford – inspected early December 2007 with visit report now made. No paperwork was available to the visiting inspectors prior to the inspection visit. Significant problems with the hotel accommodation for the inspectors were noted. No formal template for reporting inspection visits was available, but a draft version has now been produced and will be discussed by the Accreditation Committee, which has yet to meet to discuss these various operational problems.</p> <p>Cardiff – has applied for accreditation, but on self-assessment has declared a number of non-compliances. As a result the Accreditation Committee have declined to formally visit at this stage. The Accreditation Committee will discuss this issue at their next meeting.</p> <p>Olga to distribute the updated accreditation status of all centres to Steering Group members, as only Plymouth & Sheffield have full accreditation under the new scheme. Centres accredited under the pilot scheme should apply for re-accreditation under the new scheme.</p> <p>There was extensive discussion regarding whether or not centres should declare their accreditation status. Concern that this should not happen because some centres simply cannot fulfil all the necessary criteria for reasons which are outside their direct control e.g. regarding banding of nurses. It was noted that some centres have used accreditation issues as an argument or lever for extra resources. There was much concern that standards should be attainable. It was recognised that some other schemes have various levels or bands of accreditation and it was agreed that this might be considered for the UK PIN scheme by the Accreditation Committee. No firm conclusion was reached. It might be useful to look at self-assessment information from registered centres to see where there are perceived problems with accreditation in centres, both individually and collectively. It was also noted that the development of Standards of Care will be useful in this process.</p>	<p>J Unsworth</p> <p>J Unsworth R Herriot P Wood</p> <p>O Bryce</p> <p>R Herriot J Unsworth</p>
9.	Immunoglobulin supply	
	DoH/Deloitte have now produced national guidelines and a demand management plan which are available on www.intravenousimmunoglobulin.org or through the DoH website. A leaflet for patients about demand management is also available on this site, but the Steering Group thought this was a confusing document, and tended to focus on non-	

	<p>immunodeficiency diseases.</p> <p>Carrock Sewell outlined the proposals for the National Immunoglobulin Database, which is currently being evaluated by the ROCA database team. The Steering Group agreed to consider proposals from Carrock about encouraging trusts to use similar processes for blood transfusion tracking for immunoglobulin. If ratified by the Steering Group this information will be relayed to the NID team.</p> <p>The Steering Group agreed that UKPIN and the PiA should write to StHAs to insist that an immunologist is represented on regional immunoglobulin committees.</p> <p>Carl Wheeler reported that all Suppliers are meeting with PASA next week to look at uptake of the national contract. All companies have noted a reduction in sales, resulting in increased availability of both IVIg and SCIg products. It is likely that PASA and the Suppliers will return to a framework agreement in June. It was noted that there are predictions that Talecris will have big shortage of immunoglobulin in the USA next year, and that this may an impact on world supplies.</p>	<p>C Sewell</p> <p>P Wood C Hughan</p>
10.	UK PID Registry	
	<p>Bodo Grimbacher was congratulated on his Immunology Forum presentation relating to the UK PID Registry. David Edgar has agreed to chair the UK PIN PID Registry Committee and the Steering Group agreed that Bodo, Vivienne (who should apply to be a UKPIN member) and a PiA observer should sit on this Committee.</p> <p>It was noted that the legal name of the UK PIN registry needs to include the term 'ESID Registry' to avoid having to re-consent patients. MREC has requested a 'substantial amendment' application which will be submitted this week, following a review by UCL Legal Services and incorporation of their advice.</p> <p>Bodo's application for funding from the European Commission for the EU Network on Antibody Deficiency has been granted and will fund another researcher to help with data entry.</p> <p>Technically, the database and structure are now ready. Vivienne is 50% funded by the PiA. There are now 500 entries on the ESID register from the UK (third largest contributor).</p> <p>Agreed that Bodo would submit information to be placed prominently on the UK PIN website about how to enter patients on the Registry.</p>	<p>B Grimbacher</p>
11.	Pandemic influenza guidelines	
	<p>The Steering Group discussed contingency planning for influenza and a draft document containing guidance for managing PID disorders during an influenza pandemic. This guidance is intended to interface with wider information on provision of specialist Clinical Immunology services in the context of a pandemic which is being developed by the RCP. Further comments on the draft guidance were invited from Richard Herriot and it is intended that the guidance will be</p>	<p>R Herriot</p>

	placed on the website for general information in the near future.	C Sewell
12.	Specialised services national definition set	
	The draft 2008 version of Specialised Definitions Set No. 16 was circulated and discussed. A range of useful suggestions were made and further comments invited (by mid-February) for incorporation into a UK PIN response which will be communicated back to the NSCG Project Lead by the end of February.	All
13.	Relationship with the ACP	
	<p>Richard Herriot reported on the response of the ACP Council to a Briefing Note outlining the relationship between UK PIN and the ACP. Council supports the aims and objectives of UK PIN. An article for the ACP News to raise general awareness of the Network within the Association was suggested. Council stressed that any guidelines should have advisory status only and that they should have a disclaimer to this effect. The ACP was not able to provide liability cover to UK PIN for the operation of the PID Centre Accreditation Scheme.</p> <p>Arising from this, there are no direct advantages for UK PIN in a formal affiliation with the ACP but it was agreed that a professional relationship with the ACP was desirable and may bring unforeseen benefits in the future. The current relationship should therefore be continued and fostered. Similarly, it was agreed that there should be a strong partnership relationship between UK PIN and the BSI-CIAS without any move toward formal integration at this stage.</p>	
14.	AOCB	
	<p>News from the PiA</p> <p>Chris Hughan pointed out that a sensationalist article in the <i>Sun</i> about BPL has been published; no feedback on any resulting patient concern has been reported to UK PIN or the PiA.</p> <p>New members for the PiA Research Review Panels are being sought; recommendations from UK PIN would be welcomed, as would self-nominations.</p> <p>A new PiA poster for clinics has been produced (reproduced as a smaller version leaflet as well) – interested centres should request these. Review copies will be sent to the Steering Group.</p> <p>The PiA will be undertaking two pilot projects on the benefits of local advocacy and support managers to patients with PID.</p> <p>The PiA AGM will be held on 31 May 2008; a calendar of events will be circulated.</p> <p>Noted that PiA financial support from the Jeans for Genes campaign has substantially decreased this year and that this has had an adverse impact on the coming year's research funding. New CEO for the JfG campaign has been appointed.</p>	

	More regional patient events are being planned in conjunction with local centres.	
	<p>Audit of immunoglobulin therapy</p> <p>Carrock Sewell outlined a proposed audit of immunoglobulin therapy, which could also be used to examine the utility of prescribing IVIg by ideal (versus actual) body weight. The Steering Group agreed that this would be a useful audit, and that it would be reasonable to invite centres to participate and submit data from a minimum of 5 patients.</p>	C Sewell
	<p>New therapeutic approaches to the treatment of HAE</p> <p>Matthew Helbert asked if UK PIN (or the PiA) have a view on the impending licensing of a novel bradykinin receptor antagonist for HAE. The Steering Group agreed that UK PIN supports the development of new and clinically useful therapies for primary immunodeficiencies but cannot endorse individual immunomodulatory agents.</p>	
	<p>Changes to Steering Group</p> <p>The Steering Group expressed its sincere thanks to Richard Herriot (Chairman) and Fran Ashworth as this was their last meeting. It was acknowledged that UK PIN has made significant progress under Richard's skilful chairmanship, and has become an important organisation for primary immunodeficiency in the UK. Phil Wood was welcomed as the new chairman, and Jackie Moor as a representative from the RCN Immunology & Allergy Nurses Group. It was agreed that, as chair of the Guidelines Writing Group, Cathy Cale should be a member of the UKPIN Steering Group.</p>	C Cale
15.	Date and Time of Next Meeting	
	To be arranged.	O Bryce