

Minutes of the UK PIN Steering Group Meeting
Held on Monday 16 April 2007
at the Royal Society of Medicine, 1 Wimpole Street, London, W1G 0A

Present: Richard Herriot – Chairman
Chris Hughan (PiA)
Terry Flood
Bodo Grimbacher
David Edgar
Lucia Russell
Olga Bryce

Richard Herriot welcomed Terry Flood as a new member of the UK PIN Steering Group.

1	Apologies	Action
	Andrew Cant, Phil Wood, Matthew Helbert, Joe Unsworth, Carrock Sewell, Dinakantha Kumararatne, Fran Ashworth	
2	Minutes of the Previous Meeting	
	The previous minutes were accepted as a true and accurate record.	
3	Matters Arising	
3a	Finance	
	Noted that the Network finances remain in positive balance to the tune of £41,096 thanks to the donation from CSL Behring last year.	
3b	UK PIN Immunology Forum 2007	
	Good progress is being made with the organisation of this event and with finalisation of what will be a very interesting programme. Chris Hughan indicated that he would be interested in the PiA putting up a stand at the Forum and he has also had some discussions about a patient-orientated presentation within the programme, possibly around childhood/adult care transition arrangements.	UK Forum Committee C Hughan
3c	Consensus Document	
	The systematic review relevant to the patient referral document is now complete and has been submitted to <i>Clinical & Experimental Immunology</i> . Application has been made to the RCP for development of a summary guideline from this work. The managers' document developed by Matthew Helbert is largely complete and can hopefully be published in an appropriate health service journal where it will be informative, visible and useful to commissioning bodies. Richard Herriot will discuss Matthew's wishes in this regard with him. It may also be useful to organise an additional process of engagement with commissioners through a	C Hughan R Herriot M Helbert

	formal launch of this document.	
3d	Guidelines Writing Group The vacancy for a nurse to join the Guidelines Writing Group will be put forward by Lucia Russell at the nurses meeting to be held in Newcastle in May.	L Russell
3e	Subcutaneous Immunology STEP educational documentation is to be sent to all Steering Group members.	C Wheeler
3f	CSL Behring Logo The CSL Behring logo is to appear at the bottom of all electronic letterheaded UK PIN documentation. All hard-copy headed letters will also be generated with the logo at the bottom. It was agreed that it will not be necessary to order commercial, pre-printed headed paperwork. A colour printer will be needed for generation of hard copy letters in the UK PIN office. A quote will be obtained.	O Bryce
Agenda Item 4.	PID Registration/Accreditation	
	<p>A simplified registration form for all Centres has been designed and distributed. Richard Herriot sent out an e-mail requesting all Centres to register with UK PIN using this documentation with the objectives of a) gathering basic information about national workloads and service resources, b) encouraging consideration of centres to apply for UK PIN Accreditation and c) gathering information on the national picture of likely accreditation non-compliances by self-assessment. Information in relation to a) will be of central importance in discussions with the Department of Health about PID service configuration and immunoglobulin supply/demand. It has been requested that collected data should be returned to UK PIN by June 1st for collation and presentation at the Forum In November. To date, five centres have submitted data. Steering Group members agreed to give this issue their active attention.</p> <p>It would also be useful to have national information available to inform discussions at the planned RCP immunoglobulin meeting in June, but this timescale may be too optimistic. A reminder to all centres about the importance of submitting registration will be sent at the end of April.</p>	<p>All UK PID centres</p> <p>O Bryce J Unsworth R. Herriot</p>
5	UK PIN Website	
	<p>Noted that the CSL Behring logo has now been prominently placed on the website homepage.</p> <p>The updated accreditation documents are now all available through the existing upper links on the home page of the website.</p>	

6	Immunoglobulin Supply	
	<p>The DoH, with input from PASA and Deloitte, have been progressing the issue of matching demand and capacity in immunoglobulin supply by a three-pronged approach involving:</p> <ul style="list-style-type: none"> • Development of clinical guidelines for immunoglobulin usage • Creation of a national database to monitor usage and to help with forecasting • Addressing of supply & demand issues involving procurement (with PASA and the Pharmacy Market Support Group) and development of demand management plans (incorporating user access decision-making panels at Trust/SHA level) <p>Immunology representatives have been centrally involved in all three components of the DoH strategy.</p> <p>An open meeting, entitled ‘The Future Use of Immunoglobulin’ will be held at the Royal College of Physicians in London on 4/6/07 to allow multidisciplinary discussion on progress made to date, including the status of the draft clinical guidelines.</p> <p>Noted that the guidelines indicate immunoglobulin is clearly recommended as maintenance treatment for primary immunodeficiency disorders. Usage of immunoglobulin in PID disorders will not require consent from the local/SHA decision making panels which will require to be constructed as part of the demand management plan.</p> <p>Concern was expressed by Steering Committee members over the issue of impaired specific antibody production (without severe infections) and the draft recommendation that immunoglobulin is not used in this condition (with a resulting 100% decrease in usage of immunoglobulin for this indication). There is some anecdotal, individual experience of clinical benefit from treatment in a small number of paediatric cases even where apparently reasonable test vaccination responses are achieved. Concern was also expressed about the recommendations being made in the draft guidelines in respect of immune cytopenias, cases of which, in some centres, are referred primarily to Immunologists for management. These issues can be raised at the College meeting on 4th June.</p> <p>There was a general feeling that the projected decreases in usage of product for specific indications arising from implementation of the guidelines were likely to be on the optimistic side.</p>	
7	UK PID Patient Registry	
	<p>The potential for developing a register, its utility and purpose and the various models by which this may be progressed was discussed at length. There are a spectrum of views on this issue within the Steering Group and across the Immunology community. Bodo Grimbacher is proposing development of a national UK PID Register linked to the existing ESID platform. This may be more attractive than the current model of direct linkage between centres and the ESID Registry. PiA have indicated a desire to help ease the</p>	

	<p>problem of collection and entering of patient details/data into a UK Registry by funding a peripatetic individual to undertake these tasks. The ethical position of this proposal needs some consideration but it is unlikely that it raises any insurmountable problems. The process of acquiring patient consent also needs to be optimised. Richard Herriot indicated his view that consultants (particularly) in the UK needed to be actively convinced as to the value and security of a Register (whether based in the UK or centrally with ESID) and given some options as to how practical difficulties (mainly around prioritising this work) can be overcome. The new initiatives of a UK, ESID-linked Register and PiA funding of an individual to take on what are (essentially) administrative tasks offers an opportunity to go back to the Immunology community with fresh proposals for a Register. This would require development of some information to be disseminated which directly addresses questions, uncertainties and criticisms which have been previously raised and which persist. Bodo Grimbacher and David Edgar agreed to develop a draft document which outlines the functioning of a UK Register and, through a Q&A section, would provide clear answers to specific issues of utility, security, access and commercial involvement. This document will go to all UK PIN members. Noted that development of a UK Registry will require a Registry Committee to oversee its functions.</p> <p>Chris Hughan confirmed the desire of the PiA to support activities which lead to the construction of a functionally effective PID patient Register for the UK.</p>	<p>B Grimbacher D Edgar</p>
8	Influenza Planning	
	<p>The DoH has revised its UK Pandemic Influenza Contingency Plan as a UK National Framework for responding to an Influenza Pandemic. In developing the Framework document, various bodies, including the Royal College of Physicians, have been asked to highlight the challenges that a pandemic would pose to the NHS as a whole and to specialist areas of practice. Bill Egner will be leading the response to this for Immunology as a whole. Richard Herriot has agreed to put a document together relating specifically to PID patients on behalf of UK PIN. This will be integrated into the whole-specialty response.</p> <p>Noted that any information arising out of the last pandemic will be of severely limited value as PID conditions will not at that time have been significantly recognised as entities within themselves or as underlying adverse risk factors in the context of influenza virus infection.</p>	<p>R Herriot</p>
9	AOCB	
	<p>It is understood that there have been difficulties in one UK centre with accessing endoscopy for PID patients because of misconceptions about the risk category of recipients of IVIg. This has been a problem across the country for patients with haemophilia but, in light of current knowledge and the outcome of the 2005 national risk assessment process, access to invasive procedures</p>	

	<p>should not be restricted or impaired in the context of PID. Matthew Helbert has supplied useful background information in this respect directly to the centre involved. No Steering Group member was aware of similar problems in any other UK centre. Chris Hughan, similarly, had not encountered this problem from the patient perspective.</p> <p>Jackie Moor will be invited to attend the next meeting to consider joining the Steering Group as replacement nursing member for Fran Ashworth.</p> <p>Chris Hughan mentioned the recently distributed notice regarding research project funding (from GSK and routed through the PiA) and apologised for the short deadline involved. A full programme of PiA research funding will be announced in the near future with a call for applications. Approximately £250,000 of funding will be available.</p>	
10	Date and Time of Next Meeting	
	<p>It was agreed that the next meeting organised for Thursday 27 September 2007 will now be rearranged to be held in Newcastle. Olga Bryce to arrange</p>	O Bryce