Minutes of the UK PIN Steering Group Meeting
Held on Monday 20 June 2005 in Committee Room 1
at the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE

Present: Richard Herriot – Chairman
Carrock Sewell – Secretary
Dinakantha Kumararatne – Treasurer
Joe Unsworth
Alison Jones
David Webster
Lucia Russell
Fran Ashworth
Cilla Freud
Olga Bryce
Matthew Helbert

Apologies: Phil Wood
Andrew Cant

1. Previous meeting	**ACTION**
The minutes of the previous meeting held on 8 February 2005 were accepted as a true and accurate record.	
2. Matters arising	
2.1 Consultant and Nurse Exchange One trip for a nurse to gain additional clinical experience in another centre has been funded by this scheme, which is underpinned by finite resource from the PiA. Phyllis Nicoll from Aberdeen has agreed to write a report for *Insight* of how she benefited, with the aim of encouraging others to draw on the residual resource (around £1600). The scheme will be discussed further at Immunology Forum.	P Nicoll
2.2 CPD Bulletin in Immunity & Infection The future of this proposed journal remains in significant doubt, as co-editors have not yet been identified. The publisher's future general strategy for CPD journals is not clear.	
2.3 UK PIN Constitution Three major changes were accepted by the Steering Group: a) an agreement that non-UK applicants could be accepted as members if practising in the field of PID, b) a clear indication within the Constitution of the uses for which UK PIN funds can be used and c) a statement of intent within the Constitution which provides opportunity for the network membership to influence/comment on the Constitution via the website or	

through the biennial Forum. The revised constitution will be discussed at the Immunology Forum. Richard Herriot will forward the document to Carrock Sewell for posting on the website. The revised Constitution document will also be e-mailed to all UK PIN members prior to the Forum (with a covering note from Richard Herriot).	R Herriot C Sewell O Bryce R Herriot
3. Interaction with PiA	
Richard Herriot met with Chris Hughan, Chief Executive of the PiA, on 11/5/05 and 20/6/05 to discuss mechanisms for fruitful interaction between UK PIN and the PiA. Full minutes of these meetings are available separately. The principal points discussed were: - Consultant Nurse Exchange: the continued support of the PiA for this scheme was appreciated. - Patient questionnaires: the PiA asked if they could see individual completed questionnaires, to assist with targeting help at specific centres. The Steering Group did not feel that this was appropriate, but did support the PiA receiving a generic summary report of patient responses (as is already produced by Olga Bryce), providing the centre being assessed agreed and patients were made aware that the PiA may see the summary. - Specialised commissioning: the PiA is considering support for a national approach to specialised commissioning for PID services. The Steering Group felt that such a large project would be unlikely to succeed, particularly given the difficulties with large centres (e.g. London) winning support from commissioners. Significant local differences in Payment By Results (PBR) tariffs were noted, and it was agreed that the PiA may usefully consider becoming involved in seeking clarity around this from the commissioning authorities. - PiA/UK PIN Steering Group meetings: it was agreed that the PiA would have formal meetings with the UK PIN Steering Group once per year, with 1-2 additional minuted meetings between the PiA Chief executive and the UK PIN Chairman +/- Secretary per year, to be held at Alliance House. - Noted that significant progress has been made with the update of the *Antibody deficiency Consensus Document*, with input from the PiA into the managerial document. PiA input is also needed for the professional *Diagnosis & Referral Document.* - The PiA is strongly supportive of the project aimed at looking into surveillance for asymptomatic carriage of abnormal prions in PID patients exposed to UK-sourced immunoglobulin.	

- The PiA is keen to provide more activity days for children with PID, and asked how many children with PID each centre had. The Steering Group suggested asking Ruth Weldon to contact one nurse at each centre for total numbers (not names). - The PiA expressed concern that IVIg availability is likely to decrease next spring, with a rise in price predicted, as supplies are diverted to the USA. This concern was shared by the Steering Group. - The PiA was updated on the position of national registers for patients on home-based immunoglobulin treatment with a strong feeling among many UK PIN members that the registers are not accurate or comprehensive and should be discontinued in favour of locally held databases with sharing of aggregated and anonymised data at a national level (this led to the Steering Group discussing the related issue of difficulties with the national immunoglobulin adverse effects register, including data protection issues. The Steering Group agreed that all significant side effects should be reported by the Yellow Card system to the Committee for Safety of Medicines. The RCN Immunology & Allergy Nurses Group will be contacted to emphasise the importance of reporting problems with immunoglobulin products via the Yellow Card system. Alison Jones agreed to ask Ruth Weldon to pass on this message. One IVIG manufacturer has asked for a slot at the Immunology Forum to discuss adverse reactions; the Steering Group felt that input from a single supplier/producer was not ideal and Richard Herriot will discuss this with Bobby Gaspar).	R Herriot R Weldon A Jones R weldon R Herriot B Gaspar
4. PID Centre Accreditation	
4.1 Standards & Documentation The Accreditation Committee has updated the PID Centre Accreditation Standards (version 7). These were approved by the Steering Group members present. All members have one further month to make any final comments on the new standards. By this process the standards will be formally ratified at the end of July and will be posted on the website for network members to read, prior to their presentation by Joe Unsworth at the Immunology Forum. Joe Unsworth and Richard Herriot will update associated documentation (application document, inspection protocol document and guidance for inspectors) thereafter. The Steering Group discussed the issue of minimum numbers of PID patients required to constitute a PID Centre; the majority view was that an absolute number should not be set, but that appropriate experience and training was essential, and that formal links with neighbouring centres was important for single-handed centres, and should be documented.	All SG members C Sewell R Herriot J Unsworth

4.2 Assessment Visits Sheffield has now been assessed, although the paperwork is still in progress. No major problems were identified. Leeds will be assessed this week, as a combined adult and paediatric department. ***4.3 assessor Training/Refresher Training*** A learning package for assessors is still under construction. Joe Unsworth will remind Tim Wallington about this. ***4.4 Q Pulse Training*** Olga Bryce may potentially be able to receive local training in Newcastle via other NHS laboratories already using Q Pulse, or through the Immunology department in Manchester	T Wallington J Unsworth O Bryce
5. Consensus documents	
5.1 Primary immunodeficiencies: An Intro for managers This document, now in version 1.7, was well received, with only a few typographical errors to correct. David Webster will add a paragraph about 'Payment By Results' and how this will work for/impact on immunodeficiency services. This document will be discussed at a meeting in Alliance House which brings together the many stakeholders involved in its production. Concern was expressed by the Steering Group that primary care commissioning may not view PID as sufficiently important to support. The PiA has indicated that it thinks the document is extremely well written and presented but also has concerns that a) PCTs will not view commissioning of PID services as important, b) the PBR process will overtake many previous commissioning mechanisms and c) with emphasis on targets, patients with rare chronic diseases such as PID are likely to be forgotten. PiA also commented that the managers Document may benefit from a summary – in fact this is already contained within version 1.7 but will be placed more prominently at the front of the document. ***5.2 Recognition, diagnosis and management of PAD*** Further input from the PiA to the current draft is awaited.	D Webster

6. Business Case/Finance	
6.1 Current Financial position	
An account for UK PIN has been set up within Addenbrooke's NHS Trust which will undergo standard NHS financial audits. It was noted that a Finance Manager from the Trust will be required to counter-sign UK PIN expenditure, and this was accepted by the Steering Group. The current balance is in credit at around £35000 with some expenses for the Sheffield and Leeds visits pending. Members were reminded to submit all expense claims to Olga Bryce in the first instance, and Olga will send email confirmation of postage of claims to Kumar. The Group noted that Olga's contract with the Newcastle Trust, underpinned by UK PIN, has been extended by 12 months as from 30/9/05.	O Bryce
6.2 Direct costs of PID Centre accreditation visits	
Current costs were discussed. The PID Centre assessment process costs approximately £1000 per centre. There are worries that charging trusts for this, or charging a membership fee will discourage members from joining. Richard Herriot will raise these issues for discussion by the membership at the Immunology Forum. Until further funding for UK PIN can be identified and assured, the Steering Group agreed that further PID centre assessments may needed to be suspended in order to protect funding for the core structural aspects of the network. The Group felt that accreditation should be of significant interest to the PiA, and it was noted that seeking future charitable status should be a high priority, perhaps in conjunction with an existing charity.	R Herriot
6.3 Future UK PIN funding	
No developments on this issue were reported.	
7. UK PIN Membership	
There are 144 current members who have applied via the website and been accepted. One application, by a PiA Trustee, was rejected. This was discussed with and agreed by the PiA. Two applicants from overseas have been approved. The UK PIN website is receiving approximately 300-400 hits per day, of which about 5% will be automatic search engines. On the basis that it may be seen as creating divisions between centres, the Group did not support identifying accredited PID centres on the website until a larger number of centres have undergone the accreditation process. Members (who have given permission for posting of their contact details on the website) should now	All members

check their individual details for accuracy. It was agreed to post members' details by centre.	
8. Steering Group Membership	
David Webster (representing London immunologists) remits his Steering Group membership this year. Bridget Heelan will be asked by David to replace him as agreed by the Steering Group.	D Webster
Alison Jones (representing Paediatricians) also remits from Steering Group membership this year. Cathy Cale is to be asked by Alison Jones to replace her as Paediatric representative.	A Jones
9. Guidelines	
9.1 Guideline Writing Group	
Phil Wood has agreed to undertake chairing this group, once the Consensus Document for Antibody Deficiencies has been produced and he can identify more available time. Desa Lilic has agreed to join the group, which now includes: Phil Wood, Matthew Helbert, Cathy Cale, Desa Lilic, Teresa Green and Cilla Freud.	
The lack of feedback from UK PIN members remains a major problem. Possible solutions discussed included receiving CPD points for this work, emphasising that the Guidelines can be used as audit standards, and arranging discussion groups at the Immunology Forum or ESID to ratify the Guidelines.	
9.2 Home Therapy guidelines	
The new draft home therapy guidelines were accepted by the Steering Group, following removal of the absolute requirement for a normal platelet count in SCIg therapy and inclusion of appropriate referencing of other UK PIN Guidelines. The draft will now be adjusted to comply with the standard UK PIN Guideline format (no. 15). Fran Ashworth will email the final version to the Secretary for posting on the website for further discussion and feedback from members.	F Ashworth C Sewell
10. Databases	
The ESID PID Database now has MREC approval and members were reminded that they can download 'Form D' from the Corec website for submission to their own ethical committees. The passwords for this may be obtained from Oxford. Cilla Freud will ask Helen Chapel to speak for 10 minutes at the Immunology Forum about the database experience in Oxford.	C Freud H Chapel

11. UK PIN *Immunology Forum*	
Olga Bryce will remind the membership to register for this meeting using the registration form sent out by adOration, or using the form available on the UK PIN website.	O Bryce
Cilla Freud will book an 8am breakfast meeting at the conference for the UK PIN Steering Group	C Freud
12. Information leaflets	
No update on this issue.	
13. Launch of HAE Consensus Document	
Members were reminded that the HAE Consensus Document, published in the March edition of *Clinical & Experimental Immunology* will be formally launched at the Royal College of Physicians in London on 24 June.	
14. Any other business	
14.1 Accessing specialist Histopathology expertise Richard Herriot has asked the UK Histopathology community, via RCPath and ACP, for information and advice about Histopathologists who have expertise in the interpretation of tissue taken from immunodeficient patients and who may be willing to give expert opinions (or simply second opinions) to local histopathology services where difficulty is being encountered with material from patients with PID. Responses are awaited. If such individuals exist it is hoped they may wish to become members of UK PIN. ***14.2 Cord blood banking in the UK*** The PiA has raised concerns about the lack of cord blood banking currently undertaken in the UK and asked whether there was a direct role for UK PIN in emphasising the need for this to develop. Andrew Cant has indicated to the PiA that there will be a meeting held in London in the near future under the auspices of Anthony Nolan and that he and others would be pushing hard for more emphasis on collecting cord bloods for stem cell transplantation. ***14.3 Chest disease in PID*** Richard Herriot and Kumar are planning a project examining this topic and will keep Steering Group members appraised of progress.	

15. Prion Study	
MREC approval for a three-year study of prion surveillance in PID has been granted. The Steering Group received copies of the study documents for consideration. Funding has been obtained for an F grade research nurse working 4 days/week. Manchester will pilot the patient selection process.	
Next meeting	
Breakfast meeting at 8am at Immunology Forum on Saturday 19 November.	