

**Minutes of the UK PIN Steering Group Meeting
held at 11.00 am on Tuesday 20 January 2004
in the Seminar Room, Royal College of Pathologists
2 Carlton House Terrace, London**

Present: Dr Helen Chapel - Chairman
Dr Richard Herriot
Dr David Webster
Dr Alison Jones
Dr Matthew Helbert
Dr David Webster
Dr Carrock Sewell
Dr Phil Wood
Sr Fran Ashworth
Mrs Olga Bryce

Apologies: Dr Gavin Spickett
Dr Tim Wallington
Dr Andrew Cant
Dr Graham Davies
Dr Amolak Bansal
Sr Teresa Green

Helen Chapel welcomed Richard Herriot as Chairman of the UK PIN Steering Group.

Matters Arising from Previous Meeting	Action
<p>Item: PIA/02/03(a) – Consent Form – Patient’s Views</p> <p>Sister Ashworth, Sister Green, Sister Freud and Mrs Josie Drabwell met to discuss the RFH proforma for patient data for accreditation and PiA questionnaire. Totally revised the latter and taken to the PiA Trustees for approval.</p> <p>ACTION : Pilot at the Plymouth visit and to go onto the web site.</p> <p>The information for agreement to Ig therapy for patients, to be used in conjunction with Trust specific consent forms, has been amended and was approved, with some final changes.</p> <p>ACTION : To go onto the web site.</p> <p>It was suggested that the form could be run past a Trust legal services department if the Writing Group feels it appropriate.</p> <p>Item: PIA/20/03 – Databases</p> <p>Update on register and demonstration of results of analysis by Dr Graham Davies re BMT results for next forum in 2005.</p> <p>ACTION: Ask Graham Davies to write an article on the new BMTx register for Immunologists who may be interested in using the</p>	<p>J Drabwell -PiA F Ashworth T Green</p> <p>O Bryce</p> <p>F Ashworth</p> <p>O Bryce</p>

<p>SCETIDE system in the future.</p> <p>Item: From AGM Accreditation report is on the website in power point form Accreditation talk will be on the website too AGM should be in protected time at next forum – to allow better participation and for formal accountability</p> <p>Item: STC/15/03 – Appointment of New Officers Nominations are being submitted for a Paediatric Immunology Nurse to be appointed as a member of the Steering Group in February 2004. This is then followed by nominations for a nurse representative to replace Teresa Green.</p> <p>ACTION: To be reported back</p> <p>ACP liaison – Helen Chapel sent a letter to Dr Archie Malcolm but has still not received a reply.</p> <p>ACTION: Richard Herriot will chase this up.</p> <p>Item PIA/03/03 – Consultant and Nurse Exchange There is still limited uptake and it was agreed that there should be a paragraph in the Newsletter to encourage nurses to use fund for travel to other centres eg. new nurses from Leeds and consultants to use for CPD and to establish networks.</p> <p>Fran Ashworth informed the committee that she has one nurse that may be interested in the exchange. Phil Wood has 2 new nurses who would benefit.</p> <p>ACTION: To contact Tim Wallington in due course.</p> <p>It was suggested that all new and trainee nurses need to be informed about the exchange</p> <p>ACTION: A letter to go on the website.</p>	<p>T Wallington R Herriot O Bryce</p> <p>F Ashworth T Green O Bryce</p> <p>R Herriot</p> <p>T Wallington to agree with PiA as funding given for consultant visits</p> <p>F Ashworth P Wood</p> <p>F Ashworth</p>
Item STC/01/04 – Responsibility of New Officers	
<p>Secretary’s Responsibilities – agreed to uncouple the editorship of Newsletter and appoint a specific editor and small editorial board. Consider new format for Newsletter – <i>see below</i></p> <p>ACTION: Carrock Sewell and Gavin Spickett to discuss</p> <p>Steering Group members’ replacement procedures – there are sufficient members for specific projects until 2005; procedure needed, in 2005, for replacements. Done and agreed – see constitution</p> <p>Election for a new Treasurer should be undertaken soon, to allow shadowing before Tim demits office in Jan 2005</p>	<p>C Sewell G Spickett</p> <p>R Herriot</p> <p>O Bryce</p>

Item STC/05/04 – Newsletter & Immunotherapeutics Quarterly & CPD Bulletin	Action
<p>There was a discussion on whether the UKPIN Newsletter should continue as a printed version or only on the website. Agreed that an electronic version as a pdf file, which can be printed off is best.</p> <p>ACTION: ensure that members are aware of this change</p> <p>David Webster raised the question of the future of the CPD Bulletin, since sponsorship from BSACI (£6,000) was finished. Not enough individual subscriptions to be financially viable.</p> <p>ACTION: Proposal to be submitted at next meeting for combining with UKPIN Newsletter</p>	<p>O Bryce</p> <p>D Webster</p>
Item STC/02/04 – Future Accreditation applications	Action
<p>Future visits</p> <p>It was agreed that once an application for an accreditation visit is received, it is accepted that the Centre is ready for inspection. A date for inspection will be given, 3 months ahead of the visit, giving plenty of time for collation of the necessary paperwork. Quality manual to be sent to assessors once agreed ie at least 2 months ahead.</p> <p>ACTION: Appoint the Inspectors for the visits to Sheffield, Nottingham, Leeds and Plymouth.</p> <p>Plymouth in spring; Leeds in the summer; Sheffield & Hull in late autumn</p> <p>So far there are 3 (+ Leeds in the post) applications for inspection during 2004. Discussions need to be held at the next meeting on how to encourage those Centres who have expressed an interest in accreditation</p> <p>ACTION: Reminders again</p> <p>There will be revisiting for some of the Centres over the next 2 years.</p> <p>ACTION: a set of words for those reaching the standards at present without prejudice, needs to be devised meanwhile.</p> <p>UKAS</p> <p>Application will be made to UKAS re the UKPIN accreditation process. This will be included in the Business plan for 2005.</p> <p>Protocols on how to run the UK PIN office and document control are required as part of this application.</p> <p>The concerns around liability need to be considered by asking Mansel Haeney in the first instance re CPA</p> <p>SAC</p> <p>Review of reports, appointing assessors, training assessors has been</p>	<p>T Wallington</p> <p>T Wallington O Bryce</p> <p>T Wallington</p> <p>R Herriot G Spickett</p> <p>G Spickett</p> <p>H Chapel</p>

<p>undertaken by Tim Wallington, with help from Helen Chapel and Gavin Spickett</p> <p>UKAS will expect this function to be separated from the Treasurer's duties. It was agreed that an SAC be set up at once, so that the chairman can shadow Tim Wallington until he demits office as Treasurer in January 2005.</p> <p>ACTION: A small SAC of 3 appropriately experienced individuals, separate from the assessors, be appointed. Chairman to shadow Tim for 12 months</p> <p>Accreditation Assessors There was a discussion about the overlap of assessors for UKPIN, CPA, JCHMT - some assessors are on at least 2, if not all 3, of these inspection groups.</p> <p>It was agreed that this is not appropriate for a small specialty and not sustainable in view of the new consultant contract. One individual should only inspect for a max. of 2 professional bodies and preferably only one.</p> <p>ACTION: To collect the data concerning assessment visits for UKPIN, CPA, JCHMT from consultants by survey</p> <p>Accreditation assessments are time consuming - inspectors are off site for 2 days. It was agreed that an assessor's job description (stressing confidentiality) should be written, including the time off site.</p> <p>ACTION: Job description More assessor training sessions, especially for non-CPA Trained consultants.</p> <p>Accreditation Financial Matters The Treasurer, in conjunction with the Chairman and Secretary, makes all financial decisions at present. The decision as to charging for accreditation will form part of the next business plan.</p>	<p>R Herriot</p> <p>G Spickett O Bryce</p> <p>T Wallington</p>
Item STC/16/03 – Constitution Document	Action
<p>The Constitution has been revised in accordance with comments received and has been ratified by the members at the forum. It will be revised fully in 2005, in time for the next forum.</p> <p>The question of how to deselect someone from the UK PIN Committee or from membership was raised. The document shows that every UK PIN member is eligible to become a member of the committee, with the approval of the AGM. To be discussed at next meeting, as no immediate solution found.</p> <p>Membership by agreement to commitment was agreed and a draft "intention to commit" sentence and method of achieving positive membership will be proposed for the next meeting¹.</p>	<p>O Bryce</p>

¹ The final document, with a proposed sentence, was circulated 4 February 2004

<p>The UK PIN membership list will posted on to the web site, once every members have given their approval.</p> <p>ACTION: To be circulated to the Steering Group for a final reading (<i>enclosed</i>).</p>	<p>H Chapel</p>
<p>Item STC/03/04 – UK PIN Policies</p>	<p>Action</p>
<p><i>PASA-DoH Immunoglobulin bulk purchasing-</i></p> <p>PASA has chosen to delegate national purchasing to local groups for 2003/4 but are keen to pursue a national framework. Emily Costello (Department of Health) has asked if UKPIN would share the collective data on immunoglobulin usage. It was agreed that the full data was collected as confidential but that some limited information could be given</p> <p>ACTION: names of the main suppliers - BPL, Grifols, ZLB and Octapharma and a list of all Centres who provided data, once their permission has been given.</p> <p>Item: PIA/02/03c – Specialist Commissioning</p> <p>Dr Susan Schonfield to be asked to write an article for the Newsletter on the web site on “the view of accreditation from the specialist commissioners standpoint”</p> <p><i>Use of adrenaline for infusions at home –</i> The vote, following the lengthy discussions, at York was noted. It was agreed that local policies will be needed, as opposed to a national policy. This will give nurses more involvement, particularly in terms of informing the patients.</p> <p>ACTION: A note to this effect on the website.</p>	<p>H Chapel A Jones O Bryce</p> <p>O Bryce</p> <p>G Spickett</p>
<p>Item STC/16/03 – Business Case</p>	<p>Action</p>
<p>A new business case will be brought forward early this year. The current financial position was discussed and it was agreed that there is a need to obtain more funding. Dr Clive Dash [BPL] will consider renewing sponsorship, but BPL may not be able to meet the full amount needed. If other sponsors are to be asked, this will need to be done before July 2004, to get into their budgets for 2005.</p> <p>Some changes to the draft included: UK PIN are paying for the telephone conferences</p> <p>Table 2 should include:</p> <ul style="list-style-type: none"> - Consensus group - Writing Group - Income from Centres – if appropriate and if so, when? - UKAS - Cochrane Review – during this business case period 	

Emphasise the links with the PIA.	R Herriot
Agenda Item STC/18/03 – Immunoglobulin concerns	Action
<p>VCJD A CJD Incidents Panel Support Group meeting agreed that the new case of vCJD could be food related.</p> <p>Joint workshop with PiA – 3rd March 2004, to increase general education on vCJD and develop strategies for informing patients. A handful of volunteers will run PiA phone lines. Need for strategies and draft documents to be available and forwarded to Katie Oakley who is organising the event.</p> <p>ACTION: Liase with Cilla Freud in setting up a questionnaire; Invitations sent out to all UK PIN members. UK PIN recommends that one person from each Centre to attend.</p> <p>HCV The government recently announced compensation for HCV prior to 1991 but not to relatives of HCV sufferers who died.</p> <p>ACTION: letter to DoH re need for compensation without conditions ²</p>	<p>F Ashworth</p> <p>H Chapel</p>
Item PIA/02/03(f) – UK PIN Forum 2003	Action
<p>It was agreed that this meeting has been very successful and that Dr Spickett and the organising committee should be congratulated. Comments from delegates were well balanced and an improvement on previous years. Integration with nurses went well too. Some delegates wanted more emphasis on management and it was agreed that good reviews of common problems were important aspects for CPD. Speakers and chairmen needed more instruction and training.</p> <p>Earlier communications would be helpful and might result in more posters and some cases for discussion.</p> <p>The programme for 2005 needs to be reviewed by the Steering Group at least one year before the next forum.</p> <p>The question of a professional organiser would be discussed again, as the event worked out to be expensive in terms of ancillaries. It was agreed that the venue might change.</p> <p>Bobby Gaspar has offered to organise the next forum, and this was accepted with gratitude. He will be well placed to organise overseas speakers, though this would increase the costs.</p> <p>ACTION: Confirm with Dr Gaspar</p> <p>The committee expressed their appreciation and would like to thank</p>	<p>H Chapel</p>

² this was sent as the final announcement was made the following weekend

Gavin Spickett for all his hard work on the event over 4 years.	
Item STC/04/04 – Research Collaborations	Action
<p>A research subgroup of UKPIN has been proposed by Bobby Gaspar and Adrian Thrasher. It was agreed that it would be helpful.</p> <p>ACTION: Dr Gaspar be asked to prepare a short written proposal for the next meeting.</p> <p>This might include a registry for identification and consent of patients for bench research in rare diseases, a process for pilot projects in primary immunodeficiencies to encourage trainees, and means for encouraging collaborative research in the UK and in Europe. A link with ESID would form part of this proposal.</p> <p>It was also agreed that UK PIN should be promoting the health of patients with PID - needs to be focused through the centres, perhaps by means of the minimum data sets required in each centre as an Accreditation standard.</p>	H Chapel
<i>Auditing Group – Networking</i>	<p>R Herriot</p> <p>M Helbert</p>
<p>A proposal for using networks for audit was made. It was suggested that a short document for auditing the use of the UK PIN Guidelines could be done. Funding would be needed in the business case.</p> <p>Survey of use of guidelines --- audit needs resulting from visits ---- outcomes. Olga Bryce has a spreadsheet already from which the presentations at York were made. A UKPIN survey/audit tool would be useful.</p> <p>ACTION: Matthew Helbert to bring a proposal to the next meeting; also to discuss with the Writing Group at their next telephone conference in March.</p>	
Agenda Item STC/07/03 – Consensus Documents	Action
<p>As a matter of information, Richard Herriot's talk at the York Forum will be forwarded to Olga Bryce to go onto the website.</p> <p>The notes from the Consensus group meeting are available and the action points were discussed ³. It was agreed that updating of the <i>Consensus Document for the Diagnosis and Management of Patients with Primary Antibody Deficiencies</i> (1995), in light of experience of PID centres nationally with current available evidence would result in 2 documents: a <i>Guide for Managers</i> providing information on appropriate structure, operation, quality, strategy and planning of services for PID patients and a related document providing relevant, specialist information for healthcare staff on <i>Diagnosis and Referral of Patients with Primary Antibody Deficiencies</i>. A third document, relating to the management of chronic chest disease in PID, undertaken in conjunction</p>	<p>R Herriot O Bryce</p> <p>O Bryce</p>

³ the corrected version is included with the minutes

with the British Thoracic Society, is in progress.	
Date and Time of Next Meeting	
10.00 am on Tuesday 27 April 2004 at the Royal College of Pathologists, 2 Carlton House Terrace, London	