

## UK PIN STEERING GROUP MEETING

Held by Telephone Conference  
at 10.30 am on Monday 21 May 2012

Attending: David Edgar (Chairman)  
D Kumararatne (Treasurer)  
Lucia Russell (Secretary)  
Sarita Workman  
Berne Ferry  
Matthew Buckland  
Joe Unsworth  
Richard Herriot  
Sara Marshall  
Olga Bryce  
Claire Bethune  
Berne Ferry  
Helen Baxendale  
Terry Flood

<b>1.</b>	<b>Apologies</b>	<b>Action</b>
	Apologies were made for Aarn Huissoon, Fran Ashworth, Paul Williams and Scott Hackett	
<b>2.</b>	<b>Minutes of the Previous Meeting</b>	<b>Action</b>
	The minutes of the previous meeting held on 2 March 2012 were accepted as a true and accurate record.	
<b>3.</b>	<b>Matters Arising</b>	<b>Action</b>
	The PIA information on the website was discussed and it was agreed by all that it was not currently accessible. Subsequent to the meeting David Edgar has discussed with Mike Laycock and the PIA archive is now freely available on the website. He has circulated the details to members for their response.	<b>All members of the Steering Group</b>
<b>4.</b>	<b>UKPIN Membership</b>	<b>Action</b>
	There are 225 UKPIN Members to date.	
<b>5.</b>	<b>Meeting 24 March 2012 update</b>	<b>Action</b>
	The meeting held on 24 March 2012 to discuss thoughts and development relating to the closure of the PIA was discussed and the summary of the meeting will be placed on the website PIA archive page as a news item.	
<b>6.</b>	<b>Accounts</b>	<b>Action</b>
	The balance as of 20 March 2012 was £34,463.82.	<b>D Kumararatne</b>

	<p>Kumar confirmed that if we hadn't received the sum of money from the meeting in December, there would have been an over spend.</p> <p>The importance of continuing registry data entry was discussed and the range of possible methods/personnel to provide this was considered.</p> <p>Kumar suggested making an application to Genes for Genes for ongoing funding. The cost of face to face meetings against holding telephone conferences/video conference was discussed and it was decided to have one face to face meeting per year and the other meetings to be held by telephone conference.</p> <p>Funding of UKPIN was discussed. Charging a membership fee was suggested, but it was dismissed as not a good idea. It was agreed that UKPIN are still reliant on sponsorship from pharmaceutical companies and that there was a need to look forward and anticipate the likely costs of running UKPIN over the next 2-3 years.</p>	
<b>7.</b>	<b>Review of Business Plan and Questionnaire</b>	<b>Action</b>
	<p><b><i>The stated aims of UKPIN in the 2006-20 business case</i></b></p> <p>The role of the CIAS was discussed and it was agreed that under Bill Egner's leadership they would be able take things forward.</p> <p>There was recognition for the need of a formal structure for UKPIN and interest in the possibility of affiliation/developing links with the BSI as a potential host organisation. Richard Herriot explained that the BSI hosting UK PIN would in fact be a good thing, as it would be a positive relationship and that BSI have always been interested in the UKPIN as a primary focus for obtaining information about immunology, including clinical immunology and development. He also mentioned the relationship with ACP, which UK PIN have valued in the past, especially in the start up process of UKPIN, but felt that the BSI would be a very positive home for UKPIN.</p> <p>It was agreed to amend and update strategic objectives of UKPIN.</p> <p>Recognition of raising the profile of UK PIN as a national network and completion of the patient registry and centre registration projects remain the highest priorities.</p>	<p><b>A meeting has been organised to be held at the BSI in London at 11.30 on 12 June 2012 between Judith Willets CE of the BSI, Bill Egner and David Edgar</b></p>

	<p>A recognition that we need to consider as wide a funding base as possible, including traditional pharmaceutical sponsors and also exploring other funding sources, including increasing income from educational activity and attracting project specific grant support.</p> <p>There was considerable interest in increasing the frequency of the biannual UK PIN meeting to an annual event and Dovetailing the meeting with Travellers was also an option. Also combining the UK PIN meeting with the nurses' annual meeting was also an option and Lucia Russell, as a nurse representative, felt that this was a good idea, because of the difficulty in making time and obtaining funding to attend all meetings. Another suggestion was combining the annual meeting with ESID, which is held in the Spring.</p> <p>In terms of how UKPIN ought to function, there was strong support for a model whereby UKPIN would organise into a series of mini-networks of eg. 3-4 centres which would support and promote clinical audit and the development of shared clinical management protocols.</p> <p>In terms of website development, increasing availability of clinical guidelines and developing alerts for colleagues were seen as important issues.</p>	
<b>8.</b>	<b>Proposed meeting with Kenes</b>	<b>Action</b>
	<p>There was complete support for an exploratory meeting with Kenes on how they may be able to support UKPIN in its work and for agreement that working closer with a professional organisation could be in UKPIN's interest. It was agreed that the conference held in December 2012 was financially successful and generated in the region of £48,000.00. The committee also congratulates Peter Arkwright and his team for the great work on this meeting and agreed that they will be a hard act to follow. Kenes, the organisers of the conference, have expressed a wish to promote and raise the profile of UKPIN and would like to hold a strategy group meeting to help develop UKPIN's strategy. It was also suggested that the biannual meeting could be held annually, which was also suggested by Kenes, on the basis that the pharmaceutical companies were keen on this opportunity.</p>	<p><b>A meeting has been arranged with Kenes in London at 9.30 am on 12 June 2012 between Mike Foreman and David Edgar</b></p>
<b>9.</b>	<b>Specialised Commissioning</b>	
	<p>Bill Egner is working hard to put together service specifications for specialised commissioning of immunology and allergy services through the National Specialised Commissioning Clinical Reference Group for Immunology and Allergy.</p>	

	<p>David Edgar has liaised with the Department of Health in relation to UKPIN acting as the relevant professional network for PID.</p> <p>David Edgar attended a meeting at Westminster on 16 April to discuss Clinical networks and senates which emphasised the importance of raising our profile as the national network.</p>	
<b>10.</b>	<b>PID Registry and Registration</b>	
	<p>It was felt that Cathy Bangs should not only visit centres and enter data, but also train local staff on data entry. There was agreement that Cathy has a lot of experience in R&amp;D work and a monitoring/ compliance function was one that she could delivery effectively and that this is very important for the quality of the registry. The option of centres faxing or posting their data on a printed proforma basis to a central data entry point was also discussed and felt would suit most centres very well.</p>	
<b>11.</b>	<b>Centre Accreditation</b>	<b>Action</b>
	<p>Claire Bethune is keen to keep accreditation moving and there are a number of centres who are close to being ready for accreditation. She is always keen in updating Standards for accreditation. The first accreditation should take place in the autumn and Claire will get in touch with someone who has already carried out a previous inspection who will be able to update her on the process. She anticipates more inspections in the near future</p>	<b>Olga to send Claire a list of trained inspectors</b>
<b>12.</b>	<b>Writing Group</b>	<b>Action</b>
	<p>Scott Hackett informed the Steering Group that he has groups working on guidelines SCIG, IVIG, Home Therapy, Transition, HAE, CVID and HIGE. He thought it would be beneficial if all centres were approached to ask if an experienced post exam registrar from their centre could write a guideline each.</p>	
<b>13.</b>	<b>PIA Information on Website</b>	<b>Action</b>
	<p>It was agreed that the posting of the PIA information onto the website was proficient good idea, but agreed that a general introductory statement with a clearer disclaimer in relation to the documents should be shown. It was also agreed that to show other disease specific charities on the page would be beneficial.</p>	<b>David Edgar</b>

<b>14.</b>	<b>Any other Business</b>	
	<p>Gavin Spickett will be joining the Steering Group as an ex-officio and will be responsible for UKPIN Administration.</p> <p>Sarita Workman explained that the RCN Immunology and Allergy Nurse Group is now split from the RCN and are now an independent Immunology and Allergy Nurses Group. Emily Carne is now Chairperson of the group and will now be joining the UKPIN Steering Group. Kumar suggested that a UKPIN Steering Group meeting should be held at ESID as most members will be there.</p>	
<b>15.</b>	<b>Date of Next Meeting</b>	
	The next telephone conference to be arranged.	<b>Olga Bryce</b>