

**Minutes of the UK PIN Steering Group Meeting
Held on Monday 7 September 2009
in the Cavendish Room at the Royal Society of Medicine
1 Wimpole Street, London, W1G 0A**

Present: Phil Wood (Chair)
Lucia Russell (Secretary)
Chris Hughan (PiA)
Sarita Workman
Cathy Cale
David Edgar
Joe Unsworth
Carrock Sewell
Matthew Helbert
D Kumararatne,
Bodo Grimbacher
Olga Bryce

| 1. | Apologies | Action |
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| | Fran Ashworth, Aarn Huissoon, Terry Flood, Carl Wheeler (CSL Behring) | |
| 2. | Minutes of the Previous Meeting | Action |
| | The minutes of the previous meeting held on 1 June 2009 were accepted as a true and accurate record. | |
| 3. | Matters Arising | Action |
| | <p>3a. Access to UK PIN Information</p> <p>Arrangements have been made to ensure that if Olga Bryce is not available to send out emails etc. Phil Wood's secretary has a copy of the email list, which will be gravitated around whoever is chairman and the IT department at Newcastle are still working on giving access for Lucia Russell to access Olga's computer, which will also be passed to whoever takes over the role of Secretary. As people's emails have changed, mainly due to changes made by their Trust, which most people may not have realised, so this makes it difficult to communicate with them. The importance of keeping UK PIN informed of changes in address, telephone numbers and email addresses, will be addressed at the Forum.</p> <p>3b. Consensus Document for Managers</p> <p>Chris Hughan explained that due to illness, he has been away for the past 4 months and is now mainly working from home, but hopes to be back in the PiA offices in October, but for the moment it will be on a part time basis. He has</p> | P Wood |

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| | <p>been in touch with Matthew Helbert stating that he wants to progress with the Consensus document and Matthew will email the updated version to Chris and to let him know that due to the time lapse, if there is anything to be revised, so that it can now be completed, which will hopefully be by the end of the year. Matthew asked if anyone had an appropriate picture of a person self infusing, which could be used as an illustration in the document, if so could they send it to Matthew.</p> <p>3c. Relationship with the PiA</p> <p>Bodo Grimbacher was concerned regarding the decision that the PiA would be attending only one meeting per year, he felt that the involvement with the PiA was crucial. Phil Wood explained that after a long discussion with Chris, it was agreed Phil would meet with Chris prior to every UK PIN Steering Group meeting and that either Chris or David Webster would attend, if there were specific issues to be discussed involving the PiA.</p> | <p>M Helbert C Hughan</p> <p>Steering Committee</p> |
| 4. | UK PID Registry Committee Report | |
| | <p>The Steering Group were aware that the committee had held a meeting at the RSM prior to this Steering Group meeting and decided that all future meetings will also coincide with the Steering Group meetings. The main issue for discussion was that information was sent out to each Centre in June to let them know that the database registry would be up and running from August, inviting Centres to nominate a liaison person to contact Vivianne Knerr and to sign on to the registry to express their interest. Nine Centres have expressed an interest and Newcastle's approval came through within a month. It is hoped that by the end of the year there will be 9 additional Centres up and ready to enrol patients. This would probably make available between over 600 to 1000 patients. To date there are 1130 UK patients on the Register. A brief paper will now be prepared on costing implications and how many documenters will be needed. David Edgar will establish if funding is required from outside sources, which Matthew felt should come from 1 or 2 pharmacy companies as a project.</p> | <p>M Helbert D Edgar</p> |
| 5. | PIA – Update and Issues for UK PIN | Action |
| | <p>The PiA held their annual meeting on 5 September 2009 at the Novotel in London, which was worked extremely well and everyone thought it was very worthwhile. They are now considering taking either the annual meeting or smaller meetings around the regions, rather than just having everything in London. There have been very successful regional meetings either organised by the hospitals or the PiA. The PiA are now considering extended programme meetings in 2010 and would be interested in working</p> | |

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| | <p>alongside UK PIN and would accept any input UK PIN have to offer. Phil Wood suggested that in terms of feedback, UK PIN devise some sort of questionnaire for UK PIN members to complete, which Chris Hughan agreed to. They are looking for contributions from outside as they intend funding serious research and cannot afford the entry fund at this period in time. Phil Wood asked if they intended having super centres, where patients would have to travel, or to have multiple local centres. Because of the shortage of Consultants super centres may be the solution, but there are no definite plans. The situation will have to be reviewed. It was pointed out that allergy money is providing funding for both PID and allergy and that most of the expenditure is for PID patients.</p> <p>Chris Hughan informed the group that Jenny Jackson and John Satchel have both now retired from the PiA.</p> | Phil Wood |
| 6. | Finance – Update | Action |
| | <p>a. Future UK PIN funding</p> <p>Kumar has carried out a cost analysis for the past year. In past years there has been a £10,000 to £12,000 surplus. This year started with £9,500 surplus with an income of £10,000, but £27,000 has been spent, so because of the surplus UK PIN will not be going into the red in this current financial year, but because of this, to be comfortable, there is a need for a further £10,000 increase for the next year, because of further expenditure. The breakdown is as follows; salary and wages is 60%, the next biggest outlay is for travel, which is 10%, meetings, venue and meals is 10%, the website is 7.6%, the office is less than 1%.</p> <p>Phil Wood agreed that it is costly to physically get members to the meetings and that costs could be reduced by reducing the number of UK PIN Steering Group meeting to 2 physical meetings per year instead of 3 and if necessary to hold one meeting by telephone conference.</p> <p>Chris gave the committee the opportunity to hold any future meetings in the PiA boardroom, which would also reduce the cost of the meetings.</p> <p>As agreed at the last meeting, the intention is to have more than one sponsor and for UK PIN to have multiple sponsorship. Phil Wood has contacted all immunoglobulin manufacturers and had replies from 5 out of 6 of them, who have agreed at least £10,000 per year and one firm has agreed £20,000 per year for the next 2 years. Phil Wood will redraft the agreement, which serves currently, so that firms can all sign those documents, which they have all agreed to do. All firms may be keen to state that the funding would be for specific things.</p> | D Kumararatne |

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| | Phil Wood and Kumar will draw up a formal travel policy | P Wood |
| 7. | UK PIN Membership Update | Action |
| | UK PIN Membership stands at 223. Phil Wood will ask all members at the UK PIN Forum to make sure that if their email addresses have been changed, that UK PIN are informed. | P Wood |
| 8. | UK PIN Website Update | Action |
| | There is now an alphabetical list of centres listed on the website. A plan to put a map of centres is in progress | |
| 9. | Accreditation Committee Report | Action |
| | <p>a. Support for Process of Registration</p> <p>Centres who have registered are invited to re-register on a bi-annual basis and there is a system in place to trigger memories. There is a significant number who have already reregistered. There is a need to try and encourage those Centres who have never registered to do so. Most Centres have agreed that it is a worthwhile exercise, but there are still about a third of Centres who have still not registered, but have received letters from Joe Unsworth and from Phil Wood encouraging them to register. Due to Phil Wood's initiative, there is now funding for up to 20 days 'hands on' help to Centres who want to register, which was mentioned in Phil's letter sent out to Centres. This will be mentioned again at the Forum in Bath.</p> <p>It was agreed that a completely new Registration Form, for easier data collation, will be devised by Carrock Sewell, which will be set up as an excel spreadsheet to make it easier to complete the following year. There will be a master spreadsheet giving overall figures, giving an idea of how resources are distributed in the UK. The percentage figures will vary from Centre to Centre depending on the size, number of staff, number of patients etc. Hopefully, by the next Forum there should complete analysed data to present.</p> <p>b. Accreditation</p> <p>The process of reassessment is ongoing and Derriford Hospital in Plymouth is due to have their 5 year reassessment on 7/8 October 2009. The Centres who are not fully accredited because of their accreditation being carried out under the Pilot process, need to</p> | C Sewell |

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| | <p>upgraded to full accreditation. This will also be mentioned at the Forum in Bath. To encourage inspectors for accreditation, it was suggested that an interested party could attend an assessment in an observer status. It was agreed that meeting all standards and paperwork involved in accreditation and that people are busy, could put Centres off applying for accreditation, but it was also agreed that registration is a form of self assessment, which will hopefully encourage Centres to apply for accreditation.</p> | |
| 10. | DoH Guidelines and Demand Management Plan Update | Action |
| | <p>Kumar commented that when patients are treated in hospital, funding is straightforward, but when a patient sent home to be treated by Home Therapy, the Strategic Health Authority only take into account the cost of the immunology and not the cost of ancillaries etc., so there could be a problem when bills go out. Carrock Sewell commented that his understanding, is that when someone is in hospital it is still paid for by Primary Care, when the patient is sent home, the Primary Care then purchase the package, which includes the drugs and also the ancillaries and that the process is entirely the PCT's problem, but the PCT doesn't get the money unless the registration has occurred.</p> | |
| 11. | Steering Group Membership – Trainee Representation Request | Action |
| | <p>In March they established an Immunology trainee forum who have an internet space in which they can use to exchange information. They have integrated the trainee forum into ACP training days and they have a nomination process for trainees' representatives. Phil Wood will send an email to Pavel Gordin regarding nominations.</p> | P Wood |
| 12. | Writing Group Report & RCP Concise Guideline | Action |
| | <p>A telephone conference has been arranged for the Writing Group. Their target is 14 Standards to be completed, 2 of which are now on the website.</p> <p>David Edgar suggested that each centre could be asked to devise one document each, which would complete the process more quickly.</p> <p>Cathy would like to stand down as Chair of the Writing Group and further volunteers for the Writing Group will be asked for at the UK PIN Forum.</p> <p>A list of all contacts of registered centres will be emailed to Cathy.</p> | <p>P Wood</p> <p>O Bryce</p> |

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| 13. | Forum 2009 Update | Action |
| | There about 100 in total so far who have registered, but which include speakers, which is slower compared to the previous meeting. It was stated in the summer newsletter that it was now possible to register for the Forum, but there hasn't been a specific email on registration sent out. There will be another email sent out specifically giving details on the Forum and asking people to register. The programme has been approved. | P Wood |
| 14. | BSI-CIAS Update | Action |
| | From a UK PIN perspective there is no specific feed back at present | |
| 15. | Is it PID? Campaign Update | Action |
| | Data has all been collected and preliminary analysis has been carried out. The Steering Committee for the PID campaign will decide on publication and endorsed by UK PIN, which will hopefully increase awareness of PID. Phil Wood would ask Aarn Huissoon for an update but was aware that the data will be presented in poster form at the forum. | P. Wood |
| 16. | Swine Flu Update – UK PIN Position on Vaccination | Action |
| | Phil asked whether UK PIN should have a position statement on PID patients being vaccinated. It was agreed that this should be recommended, but that there is no evidence based on safety/prevention. The vaccination is only available via a GP. David Edgar suggested that the safety of the vaccination has not been established, therefore, should not be recommended, but that the general annual flu injection should be recommended. It was agreed that Bodo Grimbacher would devise a brief paragraph on behalf of UK PIN for the website stating that the vaccine will be available in the UK. | B. Grimbacher/ P. Wood |
| 17. | AOCB | Action |
| | <p>a. For cost efficiency the UK PIN Steering will be held twice per year instead of 3 times per year.</p> <p>b. There has been a proposal from Baxter to help pay for the development of a review article that can be published in the Primary Care Journal on PID. Kumar explained that a guided document has been devised for GPs, which his Trust distributed to all GPs regarding PID patients, which he will sent to Phil Wood.</p> | D Kumararatne |

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| | <p>c. vCJD Update</p> <p>Matthew Helbert stated that it has now been published that someone with haemophilia was found to have spleen infected with variant CJD. He felt this now changes the risk assessment. A further 6 year's funding for the prion study has been given, which will include money for testing. There are 50 patients recruited and 90 pieces of tissue, all of which are negative. At the end of the study means there will 500 patient years. There will be discussions held with the PiA.</p> | |
| 18. | Date of Next Meeting | Action |
| | Date and time of next meeting to be arranged. (Possibly March 2010 or at the forum). | |