

UK PIN STEERING GROUP MEETING
Held by Telephone Conference
at 2.00 pm on Friday 2 March 2012

Attending: David Edgar (Chairman)
D Kumararatne (Treasurer)
Lucia Russell (Secretary)
Aarn Huissoon
Sarita Workman
Berne Ferry
Matthew Buckland
Joe Unsworth
Scott Hackett
Richard Herriot
Sara Marshall
Olga Bryce

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| 1. | Apologies | |
| | Apologies were made for Claire Bethune, Fran Ashworth, Paul Williams, Terry Flood and Rashmi Jain | |
| 2. | Minutes of the Previous Meeting | |
| | The minutes of the previous meeting held on 9 December 2011 were accepted as a true and accurate record. | |
| 3. | Matters arising | |
| | <p style="text-align: center;"><i>Resignation of PIA CEO (effective 31 December 2011)</i></p> <p>Chris Hughan's resignation from the UK PIN Steering Group as from 31 December 2011 was recorded, which coincided with the closure of the PIA.</p> | |
| 4. | UK PIN Membership | |
| | There are 231 UK PIN Members to date. | |
| 5. | Finances | |
| | There is £36,000 left of which £10,000 is earmarked for UK PIN Registry work, £16,000 to cover salaries, £2,000 for expenses, £4,000 for travel and miscellaneous expenses. The funding agreements with the pharmaceutical companies will come to an end at the end of March 2012 and it is understood that Phil Wood had reached an agreement with them for extended funding. David Edgar will confirm this once the grade of funding has been decided. A significant amount of monies is | D Edgar |

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| | expected from the UK PIN Conference anticipated at around £40,000. | |
| 6. | Update on Patient's Representative Committee and hosting of PIA information on UKPIN Website – Meeting 24 March 2012 | |
| | <p>There is a jointly hosted meeting with the BSI to be held on 24 March 2012 in Central London, to discuss the options that are available for establishing a national patients' charity. There has been an organisation set up called UK PIPS, who have a suitable website set up and Hilary Longhurst is on their panel as a medical advisor. There is also another PID charity set up called Genetic Disorder UK, who also have their structure on the website. The meeting on 24 March 2012, which will be open to all medical staff and local patients, will be co-hosted by the 2 organisations to discuss the options for a future patients' charity. There are former trustees of the PIA who will also attend the meeting. The meeting will be jointly hosted between UK PIN and the BSI. The BSI have agreed to pay for the room hire and lunch and UK PIN will offer to help out with travel expenses and it was also suggested that Centres could also help out. This was discussed and it was decided that David Edgar would discuss with Bill Egner, the option of UK PIN paying for the room and lunch and that the BSI would pay travel expenses quoting a maximum amount for off peak travel supported by receipts.</p> <p>UK PIPS have recently decided not to attend the meeting. It is expected that Genetic Disorders UK, which was set up to run Genes for Genes will also be represented at the meeting.</p> <p>Numbers of those attending to be confirmed by 9 March 2012.</p> | |
| 7. | Information on UK PIN Website | |
| | Olga Bryce will contact Mike Laycock and Chris Hughan to find out the progress on the introduction of PIA information onto the UK PIN website. | O Bryce |
| 8. | Kenes (UK) Proposal | |
| | Kenes are keen to work with and promote UK PIN. The Steering Group agreed that the UK PIN conference in December was a great success and there was a huge amount of industry interest in sponsorship and great interest internationally. They were keen initially that UK PIN would consider additional scientific meetings and to | |

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| | <p>give sponsors greater access to the immunology community. They had several proposals involved and were interested in the core missions and anticipated future achievements of UK PIN and relationships with other organisations. Their initial proposal was a fee of £2,500 to host strategy selling sessions.</p> <p>A further meeting was held with Kenes and they are still keen to have a strategy selling meeting on a no fee basis and also offered their assistance with the UK PIN website and hoped to generate business with UK PIN in the future. Kenes see this as a business opportunity and it was agreed that their organisation skills for the UK PIN conference were very good. David Edgar will draft up a list of areas of UK PIN's future plans, circulate them to the Steering Group for comments and then have a further discussion with Michael Foreman of Kenes.</p> | D Edgar |
| 9. | PID Centre Registration and Accreditation | |
| | <p>There are 27 centres registered up to December 2011, which contains the raw data as there isn't another tool for analysing the data already there, which may be something to think about in the future, 16% registered are also accredited. There have been no other registrations since December 2011. It was agreed that Centres should be encouraged to keep their data updated to keep the registration maintained.</p> | |
| 10. | UK PID Registry Committee | |
| | <ul style="list-style-type: none"> • <i>Data entry requirements modelling</i> <p>Matthew Buckland has taken over the chair of the Registry Committee and is setting up a meeting in the near future. There is a need to model how much time and effort and how much resource is required on the complete data entry over the next 2 years. Having extracted the raw data from the registration database and then compared it with the registry data there are probably at least 600 new patients that need to go onto the registry in terms of data and then there will probably be at least, based on current practice, at least 1600 patients per year, but someone will need to travel around to enter the data, based on the Centres we have registered. There are 36 Centres of which 10 are waiting approval. Costs for a registry co-ordinator to update registry data, possibly 2-3 days per week over the next 2-3 years was discussed.</p> <p>Setting up a UK PIN Registry Study Group was discussed. A draft of suggestions will be circulated to the UK PIN Steering Group.</p> | |

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| 11. | Writing Group | |
| | <p>Scott Hackett said that steps have been taken forward with 406 documents and received agreement that they can be used for the Writing Group. He has sent out an email to the Group for their opinion on what guidelines they think should be concentrated on first. Combined guidelines were discussed (paediatrics and adults) or whether to keep them separate. The Steering Group were asked for comments on what they considered as 20 top (10-paediatrics 10-adults) useful guidelines/ideas to be sent to Scott.</p> | Steering Group |
| 12. | Specialised Commissioning | |
| | <p>UK PIN has been affiliated to the National Referencing Group for specialised immunology. UK PIN will be asked for opinions on immunology specialised services. Scott Hackett to find out who the Chair of Chairs is.</p> | S Hackett |
| 13. | Any other Business | |
| | There was no other business to discuss. | |
| 14. | Date of Next Meeting | |
| | It was decided to wait until the meeting on 24 March 2012 before a date for the next meeting to be decided. | |