

Minutes of the UK PIN Steering Group Meeting
Held on Monday 11 December 2006
at the Royal Society of Medicine, 1 Wimpole Street, London, W1G 0A

Present: Richard Herriot - Chairman
Carrock Sewell - Secretary
Dinakantha Kumararatne - Treasurer
Fran Ashworth
Olga Bryce
Cilla Freud
Bodo Grimbacher
Chris Hughan (PiA)
Lucia Russell
Carl Wheeler (ZLB Behring)

1.	Apologies	Action
	Andrew Cant, Phil Wood, Matthew Helbert, Joe Unsworth, Terry Flood	
2.	Minutes of the Previous Meeting	
	<p>The previous minutes were accepted as a true and accurate record with the following corrections:</p> <ul style="list-style-type: none"> • Change CLS Behring to CSL Behring 	O Bryce
3.	Matters Arising	
3a	<p>CSL Behring Logo on Website and Letter Head</p> <p>Noted CSL Behring logo is likely to be ready in February 2007, links will be made to CSL Behring on the website, and Carl Wheeler will forward the artwork for the new company logo to Carrock Sewell as soon as it is available. The new logo will appear on both the UK PIN website and the Network's official letterhead. The Steering Group agreed to use the current UK PIN website logo as the Network's logo on both the website and the letterhead. Carrock Sewell will commission new letterheads as soon as the CSL Behring logo is made available</p>	<p>C Wheeler</p> <p>C Sewell</p>
3b	<p>BSI-CIAS</p> <p>Noted that a recent Traveller's meeting in Birmingham voted to align UK Consultant Immunologists with the proposed new BSI Clinical Immunology and Allergy Society (accepting this name may change) as their future representative body. The RCN Nurses group may consider inviting Stephen Jolles to address their meeting in May 2007, so that informed consideration can also be given by nurses to joining this group. UK PIN awaits a formal communication from the BSI group regarding any future links.</p>	

3c	<p>Calculation of IVIg dose by ideal rather than absolute body weight</p> <p>Noted that, although prescribing immunomodulatory dose IVIg on the basis of ideal (rather than actual) body weight would save considerable quantities of IVIg, there was no firm evidence of efficacy for this. The Steering Group will await Sujoy Khan's study of body mass index and IgG levels that will investigate the relationship of serum IgG concentration and ideal or actual body mass before making any further recommendations.</p>	
3d	<p>IVIg usage post bone marrow transplantation</p> <p>Kumar undertook to distribute to the Steering Group information concerning immunoglobulin usage following BMT.</p>	Kumar
4.	PID Centre Accreditation	
4.1	<p>Noted that Plymouth has now almost reached compliance with all of the UKPIN PID Centre Accreditation standards and should be congratulated on achieving this. Full compliance is anticipated in early 2007 and they will then be fully accredited for four years. Plymouth will therefore become the first fully accredited (non-pilot phase) centre.</p>	
4.2	<p>Annual registration form – Steering Group centres were asked to pilot completion of the registration form by the end of January 2007 in order to validate the contents and layout of the proforma.</p>	All Steering Group
4.3	<p>Noted that no progress regarding indemnity cover for PID Centre Accreditation Scheme has been made. Richard Herriot will continue to work on this.</p>	R Herriot
4.4	<p>Discovery Channel programme – no news on the CVID programme yet, Carrock Sewell to remind Firefly Productions about this.</p>	C Sewell
5.	Finance	
	<p>The current financial situation at late November is in credit at £45,852</p> <p>Noted that Kumar's administrative assistant, Wendy, has left and this may result in some delays for payments. Steering Group members were asked to keep copies of all receipts, and to direct all requests for payment to Olga directly.</p>	
6	Consensus Documents	
6a	<p>Consensus Document Update (managers and professionals)</p> <p>Noted that World Immunology Day on 29th April 2007 would be later in the year for launching this document than had been intended, but could be used to bring further attention to a prior combined launch of both consensus documents, if that is possible. Bill Egner (chair of RCPATH SAC and JCI&A), David Edgar (ACP), Stephen</p>	R Herriot

	Jolles (BSI), and Joe Unsworth (BSACI CI Subcommittee) along with Judith Willets (CEO of BSI) will be contacted to discuss possible World Immunology Day activities.	
6b	Primary Immunodeficiencies for Managers The Steering Group agreed that launch of this document should ideally coincide with the Diagnosis document. Richard Herriot will ascertain Matthew Helbert's view on this.	R Herriot
7.	Membership	
	Current membership is now 178 members.	
8.	Steering Group Membership	
	Bridget Heelan has stepped down earlier than anticipated from the Steering Group, and has been replaced by Bodo Grimbacher – who will have a four-year term of office. Cilla Freud will finish working in Immunology early next year, will demit Steering Group membership in February and will need replacing, her replacement to be chosen in May at the Nursing Group meeting. Jackie Moore is considering the possibility of replacing Fran Ashworth on the Steering Group. Both will attend the next Steering Group meeting, so as to facilitate experience of the workings of the Group and possible hand-over. David Edgar, as Chairman of the ACP Immunology Committee, will join the Steering Group from today. The next PiA Medical Advisory Panel Chairman, Aarn Huissoon, will be asked to join the Steering Group after he formally takes on the role of PiA MAP Chairman in March next year.	
9.	Guidelines	
9a	Home Therapy Guidelines These were accepted and can now move from 'draft' to the 'current' guideline area on the website (the layout of the complex table still to be edited). Noted that documents 15.01 and 21.01 on the website now need to be withdrawn. Version 21.08 should be placed on the current guidelines area of the website. Olga will forward 21.08 to Carrock Sewell for table editing; Mike Laycock will forward the old versions to Olga for archiving on QPulse.	C Sewell O Bryce M Laycock
9b	Constitution of the Guideline Writing Group The Guideline Writing Group (currently comprising Phil Wood, Desa Lilic, Cathy Cale, Teresa Green) is still to meet, and requires input from another nurse member. Lucia Russell will raise this matter at the Nursing Group meeting in Newcastle in May. Bodo Grimbacher	L Russell

	volunteered to help with the review and updating of those guidelines which relate to CVID.	
9c	AGREE Criteria were discussed and it was agreed that, where possible and practical, these criteria should be used for the construction of UKPIN Guidelines, whilst accepting that (1) these Guidelines are intended for local modification, and that (2) for some Guidelines, such strict criteria may not be required.	
10.	<i>Immunology Forum 2007</i>	
	<p>The <i>Immunology Forum</i> organising committee met in November in Birmingham and the meeting is likely to be held 2-3 Nov at the Leeds Marriott hotel. Sponsorship is being sought. Concerns were expressed about the expense of holding the meeting, and whether this represents best value for money. The adOration organising fee is felt to be reasonable by the organising committee, and in direct competition with other bidders was the most competitive for the full range of services offered. It was noted that if UKPIN joined a charitable organisation such as BSI, <i>Immunology Forum</i> would be VAT exempt. The comments about the overall expense of the meeting will be communicated to the <i>Forum</i> organising committee.</p> <p>UKPIN members have been surveyed by the Forum organising committee regarding the content of the meeting, and an excellent response from >120 members has been obtained, mainly thanks to the ‘Survey Monkey’ website established by Sujoy Khan.</p> <p>The <i>Forum</i> organising committee is giving consideration to a BSI specific session at the <i>Immunology Forum</i>.</p>	
11.	Immunoglobulin Supply	
	<p>Recent interactions with Deloitte and the Department of Health were discussed. A three-pronged approach has been recommended, addressing construction of IVIg guidelines (Leader: Drew Provan), designing an emergency plan similar to that used for blood transfusion during times of blood shortages (Leader: Helen Chapel), and establishing an immunoglobulin registry to better predict future IVIg demand (Leader: Carrock Sewell). All of these are in the early stages of development. A further national commercial framework (arranged by PASA) will be established in April but the content of this is not yet known. Suggestions were discussed regarding establishing a registry in order to obtain data for accurate forecasting, such as ensuring data validity, and ensuring that IVIg oversight groups received timely and accurate feedback, and that the system should facilitate batch tracking. The involvement of a dedicated nurse or similar specialist was strongly recommended. Caution was advised about Deloitte’s possible recommendations in the final report, given the differences in the draft versus final recommendations Deloitte made regarding haemophilia. It was noted that David Edgar (ACP) and Bill Egner (JCI&A) should be included in future discussions so as to involve as many IVIg prescribing groups as possible. The Steering Group agreed to provide rapid responses to requests for help and assistance with these projects if asked by the project leaders.</p>	

	<p>Impending immunoglobulin shortages were discussed, particularly as all manufacturers at present have been forced to turn away business on a daily basis. Most centres staffed by steering group members have had severe shortages recently. Central allocation and administration of IVIg supplies was strongly supported as a viable model by the Steering Group.</p> <p>Noted – that lyophilised Sandoglobulin may also be available in the future up to 2011.</p> <p>Rumours of a pending drop in supply were discussed but no firm evidence for this prediction was available. Robust arrangements with peripheral hospitals and contingency supplies for acute use were emphasised as essential requirements.</p>	
12.	WHO List of Essential Medicines	
	<p>The IPOPI and IUIS application for the inclusion of immunoglobulin in the WHO List of Essential Medicines has been circulated, and the overwhelming support of involved groups, doctors and nurses in the UK for this inclusion was noted. A verbal presentation supporting the case for reinstatement will be made to the WHO in March.</p>	
13.	Any Other Business	
13.1	<p>Noted that PiA research grant applications will be sought in the New Year. Over £250,000 of funding is available and additional funding is also likely. Specific research areas which may be considered as priority issues include applications from nurses, collection of data for registries, quality of life studies, and pharmaco-economic studies, in addition to more standard ‘hard’ science applications. The Steering Group agreed that the UK PIN members list could be used to circulate this bid for applications from the PiA.</p>	
13.2	<p>ESID Protocols for the Investigation of Primary Immunodeficiency – the Steering Group approved the development of these protocols in a web-enabled format for non-immunologists (particularly GPs) and agreed that these could be hosted on the UK PIN website.</p>	C Sewell
13.3	<p>Noted – the production of the ‘STEP’ Subcutaneous Immunoglobulin Education Programme (Edited by Carrock Sewell), funded by an unrestricted educational grant from ZLB Behring. This programme will provide all immunology centres with teaching materials for all staff likely to be involved with subcutaneous immunoglobulin therapy. Steering Group members to be sent copies for examination.</p>	C Wheeler
14.	Date of next meeting	
	Easter 2007 and September 2007. Dates to be circulated	O Bryce