CONTACT REPORT

UKPIN



		PRIMARY IMMUNODEFICIENCY NETWORK
Client Name:	UKPIN	UKPIN, Arthur House,
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Today's date	24 th June 2015	

Meeting	UKPIN		
Participants:	David Edgar (DE) DS.Kumararatne (DK) Ravi Sargur (RS) Tomaz Garcez (TG) Sara Marshall (SM) Suzy Elcombe (SE) Claire Bethune (CB)	Peter Arkwright (PA) Bill Egner (BE)	
	MCI Roisin Jenkins (ROJE) Karen Clarke (KACL)		

	Responsibil ity	Action date
Apologies		
Stephen Jolles		
Rashmi Jain		
Matthew Buckland		
Gavin Spickett		
Emily Carne		
Scott Hackett		
Richard Herriott		
Christine Symons		
Kimberly Gilmour		
1. Introduction		
DE welcomed everyone to the meeting and thanked them for coming.		
2. Minutes of previous meeting & matters arising		
SE highlighted that she returned from maternity leave in June and not August, as listed in the minutes.		

SM stated that UKPIN has a mission statement which was prepared around the time that it was established. TG said that there was a lengthy mission statement on the existing website. TG agreed to draft a shorter version and circulate to the group.	TG	
3 .Welcome to new members		
DE welcomed Peter, Bill, Gavin, Kimberly and Christine to the UKPIN		
Steering Group.		
Ciccing Group.		
4. Transition of office bearers		
DE explained that himself and Kumar, as Chair and Treasurer, will be		
stepping down in the Autumn. He said that MCI had advised that now		
UKPIN are a registered company there is more responsibility regarding		
governance. ROJE explained that it is advisable, once DE stands down,		
he then becomes past chair for 2 years, supporting and advising the		
current chair. The same would apply to the treasurer position, although		
the transition period would be shorter.		
The group were fully supportive of this suggestion.		
ROJE also advised that UKPIN appoint an Honorary Secretary. This role		
would involve compliance with the governance of UKPIN.		
PA asked if the roles needed to be transitioned at the same time. ROJE		
replied that it was not necessary for them to happen in parallel as long as		
the roles were formalised and ratified at the AGM.		
All present agreed that they were happy with the proposals.	MCI	
DE asked that Expression of Interest forms be sent to the members of	10101	
the Steering Group who are eligible to stand.		
5. Finance		
Kumar talked through the balance sheet and explained that he and DE		
will update this and circulate to the Steering Group.		
a) Sponsorship		
DE reported on positive discussions with sponsors and confirmed		
that Shire, CSL, Octapharma, Baxalta have confirmed their		
support and he is hopeful Grifols will confirm in the near future.		
Unfortunately, BPL are unable to support UKPIN this year.		
b) Proposed membership fees		
DE reported it was previously agreed by the Steering Group that		
UKPIN would charge membership fees. MCI have provided some		
guidance on membership fees and categories. It was agreed that	DE/MO!	
DE and MCI will work on a draft proposal for fees and circulate to	DE/MCI	
the Steering Group for comment.		
PA asked if discount could be offered to those who are a member		
of other organisations. DE reported that he had had preliminary		
discussions with other organisations and would explore this		
further.		
c) Travel policy form		
DE referred to the UKPIN expenses form that was circulated		
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before the meeting. As UKPIN are about to become a registered charity, the expenses policy needs to be clear. Some discussion		

took place regarding first class rail travel and it was noted that, as a charity, UKPIN could be criticised by members for paying first class fares, although sometimes these can be cheaper than onthe-day standard fares. DE agreed that he and MCI will work on a draft policy and circulate to the Steering Group for comment. 6. Website	DE/MCI	
TG informed the group that it was important to manage the content of the new website. A lot of content on the existing website can be used, however it will be necessary to provide updated information also. He suggested forming a small content management working group. All present agreed this was a good suggestion. TG asked for volunteers to join this working group. PA indicated he would like to join. TG agreed to email all of the Steering Group members to ascertain if anyone else would like to join this group. *Post meeting note: Rashmi Jaim indicated she would like to also join the group*	TG	
Some discussion also took place around the website forums. TG agreed to clarify how membership and notifications of forums would work. At this stage, DE confirmed that Baxalta have agreed to become sole sponsor of the UKPIN website. TG confirmed that the website would be fully functional by the November UKPIN meeting/	TG	
7. UKPIN 2015		
DE informed the group that Matthew Buckland could not make this meeting but asked DE to update on his behalf. DE reported that the sponsorship of the meeting is encouraging and on target. There are ongoing discussions with other potential sponsors. He encouraged all of the Steering Group to register for the meeting and make travel arrangements. SM asked if it would be worthwhile creating a 'Who Does What' poster as previously it was well received and feedback indicated it was very useful. Agreed that this would be useful.		
8. Charitable status/bank account		
DE provided an update to the group. UKPIN are in the final stages of opening a bank account and this is hoped to be confirmed in the very near future. The charitable status application is in process and will be taken forward when the bank account and contact details are confirmed. 9. GECIP		
SM reported that there were 3 similar applications submitted and it was suggested that these groups join up to take one application forward. Sophie Hambleton is working on this and the key individuals have been identified to take this forward. PA suggested that UKPIN can help via their website and the November meeting. PA said he was happy to work with TG on the placing of GECIP on the website. DE thanked everyone involved for their work on this.		

10. Standards and Guidelines		
SM reported that she and Stephen Jolles have been unable to meet to discuss how to take this forward. After the meeting, SG will report back to the Steering	SM	
Group.		
11. IVIG Database		
DE informed the group that MDSAS and UKPIN are linking up to produce a report which he hopes will be of vales to the centres. Once a draft is complete,	DE	
DE will circulate around the Steering Group.		
12. AOB		
SM asked if UKPIN needed a Conflict of Interest policy. It was agreed that SM and BE would draft a paper and this would appear on the agenda of the next Steering Group meeting.	SM/BE	
13. Next meeting		
All agreed it would be useful to have another tele-conference in September. MCI to circulate Doodle poll to find a suitable date.	MCI	
David thanked everyone for their time.		