

# CONTACT REPORT

UKPIN



Advancing Care in Primary Immunodeficiency

<b>Client Name:</b>	UKPIN	UKPIN, Arthur House, 41 Arthur Street, Belfast, BT1 4GB Tel: +44 (0) 28 9044 6292 Fax: +44 (0) 28 9044 7110
<b>Today's date</b>	29 <sup>th</sup> January 2016	

<b>Meeting Participants:</b>	<p><b>UKPIN</b> Tomaz Garcez, Chair (TG) David Edgar (DE) Kimberly Gilmour (KG) Bill Egner (BE) Claire Bethune (CB) Ravishankar Sargur (RS) Peter Arkwright (PA)</p> <p><b>MCI</b> Roisin Jenkins (ROJE) Karen Clarke (KACL)</p>
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	Responsibility	Action date
<b>1. Introduction</b>		
TG welcomed everyone to the meeting and thanked them for attending.		
<b>2. Apologies</b>		
Apologies were received from Suzy Elcombe, Emily Carne, Richard Herriott, Gavin Spickett, Rashmi Jain, DS.Kumaratne, Christine Symons and Stephen Jolles.		
<b>3. Review of previous minutes and matters arising</b>		
All agreed that the minutes were an accurate recording of the meeting and were accepted. There were no matters arising that are not addressed in the agenda of this meeting.		
<b>4. Membership of Steering Group</b>		
TG explained that the Constitution states that the maximum number of members of the Steering Group is 15. Currently, the Steering Group has 17 members. TG informed the meeting that he has spoken separately to Kumar, the longest serving member of the Group, who has confirmed		



<p>ROJE explained that as UKPIN are now a registered company, they are required to file statutory accounts with Companies House and accountants must be appointed to prepare these. Statutory accounts are mandatory and must be filed with Companies House before the deadline of 21<sup>st</sup> July, however it is recommended that UKPIN file the accounts well in advance of this deadline.</p> <p>ROJE explained that as UKPIN have achieved charitable status, they may also wish to have their accounts audited. This is optional but it can provide associations with peace of mind. If the accounts are not audited, they will be subject to an independent exam.</p> <p>MCI have spoken with Rashmi regarding the statutory accounts and provided a breakdown of the costs associated with this. These costs were circulated in a paper to the Steering Group prior to the meeting.</p> <p>TG asked all present if they were in agreement with the costs outlined in the paper. All agreed to proceed with the proposal.</p> <p>PA noted that UKPIN require a budget for the coming year. MCI require figures from UKPIN to populate a budget for 2016/17. TG noted that a new Treasurer was not long in office. TG will speak to RJ with regards to working with MCI in preparing a budget forecast. TG explained that a lot of work has already been put into getting these accounts in order and it was difficult for MCI and UKPIN to get an accurate picture from the previous information.</p> <p>PA asked when the next set of accounts would be available. ROJE informed that they were due to be sent to the Treasurer in mid February</p> <p>PA asked if the management accounts could be presented in a simpler format. TG noted that this could be done for the AGM.</p> <p>BE commented that the accounts need to be filed in a standard format. He asked the group to be aware that this is the first time they have seen accounts like these for UKPIN.</p> <p>TG asked the group to vote on the accounts proposal. All members supported the preparation of audited accounts.</p> <p><u>Registry</u> The Registry report was noted.</p> <p>TG asked that, as the Registry is one of UKPIN's biggest expenses, if the Steering Group consider the configuration of the staff appropriate. Some discussion took place on if it would be more practical for Registry staff to be based in different parts of the UK as opposed to both in the North West. KG noted that it is important to understand which centres they are entering data for so that a decision can be made on the best location of the staff.</p>	<p>TG/RJ/MCI</p>	<p>End February /March</p>
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<p>CB suggested that a report from the Registry staff on their work would be very useful. TG to ask Cathy Bangs to produce a report for each Steering Group meeting. TG to follow up with Matthew Buckland regarding David Guzman and reporting on his work.</p> <p>RS asked if it was necessary for a nurse to enter the data into the Registry. KG agreed and said she believed that the data entry could be completed by a person at band 3 – 4.</p> <p>TG to follow this up with Cathy Bangs and Matthew Buckland.</p>	<p><b>TG</b></p>	<p><b>1<sup>st</sup> February</b></p>
<p><u>Accreditation</u> CB explained that accreditation was now with the QPIDS scheme. The first training day was successful with good feedback. There are currently 21 centres registered. The Clinical Guidelines Group will report back to UKPIN at each meeting.</p>	<p><b>TG</b></p>	<p><b>5<sup>th</sup> February</b></p>
<p><u>Guidelines</u> TG asked if everyone had the opportunity to note Stephen Jolles' paper and BE's response. Some discussion took place and concerns about the proposal were raised. DE noted that there has been limited progress on developing guidelines over a number of years. DE stated that BSI have been keen to work with UKPIN on guidelines. TG explained that BSI are not keen on industry funding for guidelines and another non-industry source would be needed.</p>		
<p>TG noted that the majority of the Steering Group, including those who sent their responses prior to the meeting, are not in favour of this proposal. TG to feed this back to Stephen Jolles (SJ). SJ to be asked to continue to lead on a guidelines pilot proposal for UKPIN in collaboration with BSI (majority vote in support of this), using finances not from an industry source.</p>	<p><b>TG</b></p>	<p><b>5<sup>th</sup> February</b></p>
<p>Steering Group suggested that the money pledged from industry to UKPIN for the proposal could be redirected as general UKPIN funding and would be appreciative if SJ could discuss this with the companies and to confirm with the companies that UKPIN would not be progressing with the proposal.</p>		
<p><u>UKPIN 2017</u> KG gave a brief update on the planning of the meeting and confirmed that she will arrange a conference call for the planning committee and keep the Steering Group informed.</p> <p>KG left the meeting at this point.</p>		
<p><u>Website</u> TG noted that there has been a lot of progress on the website and the membership platform will be launched week beginning 1<sup>st</sup> February.</p>		

<p>Members will get an email with their individual log in details and certain areas of the website will be members only.</p> <p>TG explained that an information and communications lead is required to take forward the work with the website and newsletter. PA had expressed an interest and would be supported by CB as Honorary Secretary. All agreed they were happy with this decision.</p> <p>TG noted that he would like to identify a person from the wider membership who could focus on social media. He asked that if any members of the Steering Group knew of someone who may be interested, to send their details to PA and CB.</p>	<b>All</b>	<b>Ongoing</b>
<b>6. Constitution and Terms</b>		
<p>TG asked the Steering Group to note the papers circulated prior to the meeting. He asked for feedback on the draft Code of Conduct for UKPIN and for any suggestions, amendments or additions to be sent to the Chair.</p>	<b>All</b>	<b>Ongoing</b>
<b>7. Information Management and Communications</b>		
<p>This item was covered under Item 5: Website.</p>		
<b>8. AOB</b>		
<p><u>Department of Health Stakeholder Consultation Response</u> TG asked the meeting to note the response to the consultation on C1 Inhibitor prophylaxis, which was circulated prior to the meeting.</p> <p><u>Newsletter Proposal</u> TG noted that Emily Carne and Gavin Spickett had sent their support of this proposal via email. All agreed to proceed with the proposal.</p> <p><u>WHO HAE International Alliance Invitation</u> All agreed to support this.</p> <p><u>Network</u> CB noted that she is happy to look into other specialities' networks, what works well and not so well. She asked if everyone was happy for her to proceed with this on behalf of UKPIN. All agreed.</p> <p>DE confirmed that there is data on where the networks are. TG will send a link to the website to CB.</p>	<b>TG</b>	<b>5<sup>th</sup> February</b>
<b>9. Next Meeting</b>		
<p>MCI will circulate a Doodle poll for the next meeting, for end of March/April.</p> <p>TG explained that normally a Stakeholder Engagement meeting would be</p>	<b>MCI</b>	<b>End February</b>

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