



**Steering Group Committee**  
**The United Kingdom Primary Immunodeficiency Network (UKPIN)**  
**which took place on**  
**Friday 29<sup>th</sup> March 2019**  
**via teleconference**

**Attendance:**

The meeting was attended by: Kimberley Gilmour (KG), Tomaz Garcez (TG), Suzie Elcombe (SE), Alex Richter (AR), Ravishankar Sargur (RS), Patrick Yong (PY), Catherine Stroud (CS), Sarah Denman (SD), Jill Edmonds (JE), Shuayb Elkhailifa (ShE) and Otto Balsiger (OB) from the British Society for Immunology (BSI).

Apologises:

Lisa Devlin (LD), Rashmi Jain (RJ), Sinisa Savic (SS), Bill |Egner (BE), Austin Worth (AW)

**1. Welcome**

Tomaz Garcez (TG), Chairman of UKPIN, welcomed everyone to the meeting, especially the new members.

**2. Review of previous minutes**

TG reported there were still a few issues with the minutes of the last Steering Group meeting. He will circulate them.

**3. Matters Arising**

- a) It was agreed that there would be a 40% discount on 2 years membership fees with the conference ticket for the biennial meeting
- b) SE reported work on database is in progress. Needs to arrange a day with Sarah from BSI to go over things
- c) Funding policy is in progress
- d) Work on the website is pending
- e) HAE Network. Need to discuss funding with Rashmi. In terms of governance will need to be set up as a sub-committee
- f) SS reported that contact was made with Anthony Nolan re bone marrow – no need for more advanced linkage
- g) TG confirmed no one had volunteered for the Chair and Treasurer roles that have been extended for an extra year to December 2019. TG again asked for interest to be put forward, there is a critical need for succession planning
- h) OB reported that a draft risk register will be presented at the next meeting

#### 4. Reports

- a) Treasurer's report  
In RJ's absence OB gave a quick report. There is a surplus of £25k for the year to date and a current Balance Sheet value of £118k. No significant issues to report
- b) UKPIN Funding  
TG reported in LD absence, good progress has been made with Octapharma, though their level of support reduces from £27k to £10k. This funding will be to support registry development
- c) Registry  
Helen will be leaving in July/August. An overlap with the new person of 1-2 months has been agreed by the Directors
- d) Accreditation  
RS went through his report. Will need to tweak website
- e) Guidelines  
First set have been completed and published  
Meeting to be set up for the second set. It was reported that costs have increased to £7k each for BSI and UKPIN.
- f) Website  
It was reported that most users are from the UK and visits are mainly between 10am to 4pm (within working hours) and were on desktop computers.

The current structure was discussed, the website is not intuitive, however this would involve a significant investment. It was decided to stick with current structure.

**Action:** To be discussed in more detail in December

- g) UKPIN 2019  
TG summarised the written report, in the absence of SS, programme almost complete
- h) Nursing competencies  
JE reported there is only one pediatric nurse on committee - any suggestions of one other to join would be welcome. SE suggested could ask Lisa in Newcastle and give feedback to JE
- i) Immunoglobulin Supply  
Committee has engaged with NHS England on this issue. NHS England have signed off immunoglobulin price increase of £50m.  
The survey of members re action to take closes on Tuesday, current preference is to write to the Secretary of State for Health.  
Questions considered:
  - Are there any objections to smaller group drafting a letter to the Secretary of State of health providing results of our survey? - No
  - Does anyone feel that a different or alternative action should be taken? - No
  - Is the committee happy to approve Sarah as the representative of UKPIN on this issue? – Yes

j) HAE UK Network

It was decided to identify key priorities of data and send out to encourage people to complete their returns

**5. AOBs**

a) Immunology Training

The proposed changes were reported, RS to provide written report if required. RS to draft letter for UKPIN to send.

b) Education funding of ACP days

The funding of ACP educational days was discussed. ACP is working with the BSI to resolve.

c) ShE presented ideas for education and happy to contribute / lead on this – committee in support.

**6. Next meeting**

To be held in 3 months' time