



Steering Group Committee
The United Kingdom Primary Immunodeficiency Network (UKPIN)
which took place on
Wednesday 14th November 2018
at
Citadines, Holborn

Attendance:

UKPIN trustees: Sarah Denman (SD), Sinisa Savic (SS), Ravishankar Sargur (RS), Jill Edmonds (JE), Tomaz Garcez (TG), Kimberley Gilmour (KG), Rashmi Jain (RJ), Peter Arkwright (PA), Austen Worth (AW), Suzy Elcombe (SE), Claire Bethune (CB)
BSI: Otto Balsiger (OB), Kajal Tanna (KT)

1. Welcome

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

2. Review of previous minutes and matters arising

The minutes of the last meeting were reviewed and approved. Matters arising were as follows.

CB confirmed that QPIDS will be taking on network information.

There has not been much progress on flyers and impact on membership, but it was agreed that members can pay for membership and meeting together as a two-year package, therefore the Steering Group concluded that there was no need for flyers. RJ will be asked to consider revised fees.

It was also discussed that work needed to be undertaken on UKPIN membership payments; SE, KT and Sarah Green from BSI were to look at membership payments and categories

Paediatric nurses are to be involved in nursing competency development, and AW is to provide names to JE.

There has not been any progress on funding policy. BE and LD to progress.

The guideline writing group has completed the first guideline. The second guideline is to progress on immunoglobulin treatment. It was agreed by SG for CB to progress with recruitment and selection of membership of the steering group for the second guideline.

It was also noted that nursing involvement is agreed for the 2019 meeting. SS and BSI are to liaise i.e. Save the Date email which should also be sent to BSI members.

The communications page on website is now going to be moved to members only; this is in progress. KG and BSI to progress.

HAE network proposal is pending from RJ and Patrick Yong – will need input from BSI on costs of secretariat once completed. OB to review once proposal completed.

There has been a meeting which has been set up with Anthony Nolan regarding bone marrow donors and this is for feedback at the next meeting pending discussions with Anthony Nolan. SS to update on his patient.

3. Chair Report

Trustees

TG reported that there are 3 trustee applications were received, however upon checking the info@UKPIN inbox, it was discovered that more applications had been received and a re-election is needed. Patrick was approved as a new trustee based on his leadership of the HAE network which is likely to be a subcommittee of UKPIN.

CB stepped down as Honorary Secretary, and TG welcomed SE into this role. RJ and TG have come to the end of their terms but have agreed to continue in their roles for another year. TG invited applications for both roles, however none were received. TG will discuss his succession with individual members of the committee.

KG agreed to take on website.

Treasurers report

RJ gave a short presentation on the UKPIN finances; net assets have risen from £60k to £95k this year; this was following an increase in net income of £33k. At the end of October 2018, the bank had a healthy balance of £89k.

Accreditation and guidelines

34 out of 36 centres are registered and 11 are accredited; QPIDS standards have been developed from UKPIN standards. The aim for next year is for 50% of services to have been accredited by the UKPIN meeting in 2019, and several visits are already booked.

The 2017 census has been circulated to participating centres and 2018 responses have now been collected; the report is in preparation. 2018 staffing results were as follows; 8 unfilled posts, 14 retiring in next few years.

The first guidelines have been written, and the same process will apply for creating and implementing the next guidelines.

UKPID Registry

There were 6,675 patients entered in total, and a 2018 joint publication with MDSAS, with APDS having a joint publication with ESID. The registry was then successfully adopted by NIHR LCRN and has been since August 2018. Sites should now have access to a local CRN resource to support recruitment and data entry.

Website

There were around 2,000 views per month which then increased to 5,000 around the time of the UKPIN meeting, and most of these views are either from the UK or USA. Half of views were done via people's phone, and half via pc. The main areas that people visit on the website are meetings, registry, membership and guidelines.

UKPIN meeting 2019

The dates have been decided for 5th & 6th December 2019, and the first day plenary sessions will be shared with BSI, like 2017. There will be more focus on UK based clinical practice.

Risk & Opportunities register

OB & SE are to meet to discuss the development of a UKPIN risk register.

AOB

TG shared correspondence from UKPIPS and it was agreed that UKPIN had tried working with both patient groups and that it was important to work with all patient groups. TG concluded that UKPIN is happy to be involved but this is not the right time.

Next meetings to be scheduled from early 2019

TG closed the meeting