



Advancing Care in Primary Immunodeficiency

Annual General Meeting of
The United Kingdom Primary Immunodeficiency Network (UKPIN)
which took place on
Wednesday 16th November 2016
at
BMA House, London

Attendance: The meeting was attended by 13 members of UKPIN.

1. Welcome

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

2. Agreement and proposal of minutes

The minutes of the 2015 AGM were proposed and agreed.

3. Reports

Chairman's Report

TG reported on the progress made by UKPIN in the past year. He noted developments with Guidelines, Registry and Accreditation. Some of the challenges faced included funding for UKPIN activities and Statutory Pharmaceutical Pricing Scheme.

Treasurer's Report

Rashmi Jain (RJ) reported on the financial position of UKPIN:

Total income:£229,351.24

Total expenditure:£235,183.22

Current balance: £128,237.53

She noted the importance of continued support from sponsors and the introduction of membership fees as essential elements to ensure UKPIN can continue activities.

Accreditation

Claire Bethune (CB) reported that:

- 25 Immunology services have now registered
- 5 previously UKPIN accredited successfully renewed (3 requiring further information)

The future of the scheme includes getting all centres registered and an annual review for all registered centres will take place in May 2017.

Registry

Matthew Buckland (MB) reported that 4297 patients have been entered in total. The Registry development includes a new website, combined reporting with MDSAS and simplified registration with access to historical data. Reduced staffing means that centres are only being visited once per year. For the future, MB would like to consider long term funding options and increased staff.

Guidelines

CB confirmed that a single first guideline is planned with combined support from UKPIN and BSI.

The area supported for development is

“Management of non-infectious complications of COVID”

To include: GI complications (stomach/bowel/liver)

Lung complications: interstitial lung disease/granulomatous lung disease

Autoimmune cytopenias or Haematological complications.

- The next steps are to
- Review and agree the scope of the guideline to determine whether all of the topics in the current title can be included
- Review feedback regarding the memorandum of understanding and potential agreement with National Guideline Centre, Royal College of Physicians
- Arrange the first meeting of the group

UKPIN 2017 Meeting

Kimberly Gilmour (KG) reported that the meeting has been confirmed for 7th/8th December 2017. Thursday 7th will be a joint day with BSI and this will be held at the Dome Brighton. Friday 8th will be UKPIN only.

The next steps include developing a Memorandum of Understanding with BSI and to begin to develop the programme with the Committee.

Website

Peter Arkwright (PA) informed the meeting that the website has been live for one year. The statistics suggest that the website traffic could be improved but this requires engaging content. He noted that visits to the website increase following the UKPIN newsletter.

4. Ratification of new members

The following members were approved for membership of UKPIN:

Tan Tyng
Simon Craig
Nisha Verma
Debbi Cook
Catherine
Waruiru
Julia Jones
Maaïke Kusters
Ivonne Jones
Victoria
Blackeley
Alex Richter

5. AOB
There was no other business.

TG thanked all present for attending and closed the meeting.