



**UKPIN Stakeholder Meeting**  
**Wednesday 14<sup>th</sup> November 2018**  
**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)

Stakeholders – industry: Jane Shepard (JS – LFB), Ed Porter (EP – CSL Behring), Tom Carney (TC – Biotest), Sergio Gavilan (SG – Biotest), Irm Saleem (IS – Octapharma), Neil McCallum (NM – Representing Pharming)

BSI: Kajal Tanna (KT)

**Welcome**

TG gave a short update on UKPIN and their objectives/aims which are aligned with their charitable objectives which are advancement of care for PID, including the development of best practice approaches to diagnosis and management, guideline development, registry and education. UKPIN's major achievements include the registry, accreditation and the census.

TG advised there would be updates on accreditation and guidelines, registry and UKPIN meeting.

A letter has been sent to NHS-E and has been consigned by BSI/Patient groups and nursing groups, and the response is to be circulated the following week.

**Accreditation and census**

There have been new standards introduced for 2019. CB explained the process which is registration, self-assessment, site visit (5 yearly), actions, recommendations and accreditations. CB advised that centres are improving from being part of accreditation and the aim for next year is to have 50% of services accredited by the UKPIN meeting in 2019. The 2017 census has been circulated to participating centres and 2018 responses have been collected with the report being in preparation.

**Registry**

The aim is to capture all patients with primary immunodeficiency/initial diagnosis, however there have been challenges; C Bangs has retired and recruitment has taken 1 year.

Data analysis and development has been challenging with limited data. NIHR adopted in August 2018 and sites should all have access to a local CRN resource to support recruitment and data entry. Collaborative grants such as PID-BRIDGE are in progress and UKPIN are open to new projects for collaboration. There are calls to trainee immunologists to approach registry.

### **UKPIN/BSI guidelines**

CB provided update on guidelines; Delphi process was undertaken, and the stats were sent to 91 immunology consultants for approval/disapproval. The same process will take place for next guidelines and applications were invited for steering group committee members. Use of replacement immunoglobulin for patients with antibody deficiency (primary and secondary)- these will be clinical guidelines rather than commissioning guidelines.

### **UKPIN 2017 meeting**

An update was provided regarding the feedback for the 2017 UKPIN meeting which took place at the BSI Congress. The meeting met the budget expectations and received good feedback from participants.

Sponsors advised that they felt that the meeting achieved objectives. A small group felt that it wasn't important to sponsor at UKPIN meeting however there was a 40% increase in new sponsors. Out of 181 delegates, 59 of these were sponsors.

### **UKPIN 2019 meeting**

The 2019 UKPIN meeting will be held on 5th & 6th December 2019 in Liverpool, and there will be more focus on UK based clinical practice. There will also be new sessions such as a Grant round, and CRG update, and first day plenary sessions will be shared with the BSI.

One point discussed was can there be industry sponsorship?

### **Website**

The website has been completely revamped, and visitors are either UK or USA based. The main areas that people visit on the website are meetings, registry, membership and guidelines.

### **Future of UKPIN**

TG explained the future of UKPIN and its intent to continue to support QPIDS and the annual census. UKPIN will continue to support development of clinical guidelines and support education. They will develop the registry with level 2 data and produce joint registry and database reports. They also intend to grow their membership and ensure that there are no Brexit implications on collaboration with ESD etc.

### **AOB & questions**

TG thanked stakeholders for their support and invited them to stay for informal talks with Trustees.