UKPIN Patient Groups Meeting

Wednesday 14th 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 – patient groups: Susan Walsh (SW – PIDUK), Claire Hennessey (CH – MaxAppeal), Liz McCartey (LM – UKPIPS), Rebecca Griffiths (RG – UKPIPS)

BSI: Kajal Tanna (KT)

Welcome

TG welcomed all to the meeting. Previously this meeting was a joint meeting with patient groups but TG felt it would work better to meet with the two groups seperately.

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 managment, 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.

TG advised that UKPIN has only changed with written approval of the Commission and much more detail is available in Constitution, and the key challenges for UKPIN not changed much since last year. The main financial challenge remains the registry, and is primarily staffing costs.

Registry

AW gave brief review on registry; the registry can be used as a resource for improving patient care, and patients are to provide their consent to use data. The histocytosis sub registry has been approved and awaiting UK implementation.

Accreditation and census

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

Registry

The aim is to capture all patients with primary immunodeficiency/initial diagnosis. Challenges have included the fact that C Bangs has retired so recruitment has taken 1 year, and 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 in progress. UKPIN open to new projects for collaboration and calls to trainee immunologists to approach registry.

UKPIN/BSI guidelines

CB provided update on guidelines. Delphi process was undertaken and the stats sent to 91 immunology consutants for approval/dissaproval. The same process will be undertaken for next guidelines and applications invited for steering group commitee members. “The use of replacement immunoglobin for patients with antibody deficiency (primary and secondary)”; these will be clinical guidelines rather than commissioning guidelines.

SW expressed concerns about membership fees and advised that most nurses that she has asked are not members of UKPIN due to the fee’s. TG advised that the fee’s are not much and guideline work is something we do not get funding for, this fee also includes the meeting.

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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 wasnt 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

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. First day plenary sessions will be shared with the BSI.

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 ESID etc.

AOB & questions

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