



Annual General Meeting of
The United Kingdom Primary Immunodeficiency Network (UKPIN)
which took place on
Thursday 19th November 2015
at
Assembly Buildings, Belfast.

Attendance: The meeting was attended by 66 members of UKPIN.

1. Welcome

Dr David Edgar, (DE) Chairman, UKPIN, welcomed everyone to the AGM.

2. Agreement and proposal of minutes

DE explained that an AGM was not held in 2014 and that there are no official minutes from the 2013 AGM. However, the slide presentations will be stored as a record of the meeting

3. Reports

Chairman's Report

DE reported that there has been a lot of change for UKPIN within the past year.

The previous UKPIN association management company were declared bankrupt in Oct 2014, however, after considering tenders from a number of companies we appointed a very experienced association management company, MCI, in March 2015.

HQIP ceased to fund the UKPID Registry in July 2014.

UKPIN are now registered at Companies House.

UKPIN achieved charitable status on 18/11/2015.

Reviewing the objectives set out in 2014:

UKPIN have now achieved

- Charitable status.
- Supported Scott Hackett with Standards & Guidelines.
- Completed network modelling.
- Continued with the patient registry and accreditation.
- Steering group refreshed: identify succession planning and links with other organisations.
- Pursued discussions re accreditation.

Treasurers Report

Dr Dinakantha Kumararatne (DK) reported:

October 2014 –October 2015

Total income: £347,559.05

Total expenditure: £179,318.76

Balance: £168,240.29

- Change in association management company and rescue of funds to a holding account with solicitors.
- VAT registered: Figures will change slightly as we are currently in process of reclaiming VAT from October 2014.
- Accreditation: Payment of £30,000 to Royal College of Physicians.

Registry Report

DE reported:

- New Registry Structure Live 1/10/15
- Pre-Transfer 4,000 Pts in the UK registry
- Main Task is to Validate Entries
 - Confirm living status
 - Confirm diagnosis
- Level 3 projects – 1 active at present
- Staffing – Cathy Bangs/Stephanie Farrell/David Guzman
- Calls for Level 3 Projects/Research encouraged

Accreditation Report

DE reported:

- Developed from UKPIN accreditation scheme
- Now adopted by RCP accreditation unit
- Centre Registration from 19th November 2015
 - Webtool access for registration and accreditation
 - Training days “How to become accredited” being arranged for early 2016
- Application for assessors open
- For more information visit the QPIDS stand in the exhibition area at the conference
- www.qpids.org.uk

GeCIP Update

DE reported:

- UKPIN bid to form a GECIP for PID approved to proceed to 2nd stage
- Involves > 120 UK clinicians and scientists
- The benefits of 100k genome project delivered for the benefit of PID patients
- Opportunity to improve and enhance diagnostics
- Led by Prof Sophie Hambleton (Newcastle) & Prof Sara Marshall (Dundee) on behalf of UKPIN

4. Membership Fees

DE reported that following comprehensive discussions, the UKPIN Steering Group have decided to introduce membership fees. The fees will be implemented mid 2016.

5. Ratification of Office Bearers

DE informed the meeting that vacancies had arisen for the positions of Chair, Honorary Secretary and Treasurer. The Steering Group were asked to submit expressions of interest for these positions. He confirmed that 3 expression of interests were submitted, once for each position of office.

The 3 members are:

Chair: Tomaz Garcez

Honorary Secretary: Claire Bethune

Treasurer: Rashmi Jain

DE asked if anyone present had any objections for these members to be appointed to the positions. There were no objections and the decision was ratified by attendees.

6. Launch of new website and identity

Tomaz Garcez (TG) informed the meeting that UKPIN had been working on a new brand identity and website. TG displayed the new UKPIN logo and website for the members present.

7. AOB

1. A question was raised by Desa Lilic:

Should UKPIN identify and support a single patient support group?

TG answered that UKPIN is fully aware of the issues with multiple patient groups, and agree that the situation was far from ideal, but that UKPIN would work with all patient support groups

2. A question was raised by Paul Williams

He asked about fees and how UKPIN would ensure financial viability

TG explained that we did not have the full financial picture at present due to recent events and that we would be reviewing finances in the first couple of months of 2016

TG thanked all present for attending and closed the meeting.