# Message from the Chair of UKPIN

Welcome to the inaugural quarterly UKPIN e-newsletter. I start my Chairmanship of UKPIN as a newly registered Company and Charity. We have a new constitution along with a new corporate identity and website. The recent developments of UKPIN have only been possible due to the commitment and dedication of our membership and Steering Committee members and the support from our sponsors.

Three new officers of UKPIN were introduced at the <u>annual general meeting</u> held in November 2015. I would like to thank David, Matthew and Kumar for all of their contributions to developing UKPIN over the last decade!



Tomaz Garcez UKPIN Chair



## Who's Who on the Steering Committee

Please <u>click here</u> to find out more about the members of the current UKPIN Steering Committee.



#### Website

The <u>UKPIN website</u> has been redesigned and offers an overall greater user experience and access to information as mentioned above. The interest groups, where cases can be shared and discussed, research collaboration can start and UKPIN committee work can be discussed are accessible from the main page. It takes a number of clicks to get to the actual content of the groups from the home page and we are working to reduce this. The membership directory

is also in development, which relies on an updated profile for each member. If you haven't yet logged into the membership profile pages please do so and update your information. Your userID and password were sent by email on 2/2/16 (email subject "Your New UKPIN Website Login Details").

## Registry

The UKPID Registry now includes almost all of the PID centres in the UK. The staff supporting the registry, and funded by UKPIN, have been instrumental in ensuring the success of the registry. Please read the <u>report</u> provided by Catherine Bangs on the registry and review the <u>live data</u> on the website.

#### **QPIDS Accreditation**

Quality in Primary Immunodeficiency Services (QPIDS) accreditation has moved to the RCP accreditation unit under the supervision of UKPIN and clinically led by Claire Bethune. Updates on the status of accreditation and registration can be found on the <a href="UKPIN">UKPIN</a> and <a href="QPIDS">QPIDS</a> websites. Please take the time to read the <a href="update">update</a> provided by Tim Shaw.

#### **Biennial Conference**

The UKPIN biennial conference was held in Belfast in November 2015 and was a great success. Please see the **Meeting Organising Group Report** provided by Matthew Buckland for more details on the facts of the meeting including attendance data. As with the 2013 conference the sessions were video recorded and are available to members on the <u>website</u>. Photos and <u>poster abstracts</u> are also available for members to view online. Please take the time to read the <u>report</u> by Suzanne Elcombe providing a **trainee perspective on the meeting**. The 2017 meeting will take place in Brighton on the 7th and 8th of December and follows immediately after the BSI annual conference (4th to 7th December), with a single overlapping day. **Please save the date**. The organising committee is being led by Kimberly Gilmour in collaboration with the BSI.

#### **Clinical Guidelines**

UKPIN is working with BSI and other professional organisations in the development of clinical guidelines for primary immunodeficiency diseases. Any relevant publications will be linked on the <u>website</u>. If you would like to be involved in the UKPIN:BSI guidelines committee please <u>contact me</u> so I can provide you with more information. We are looking for all levels of UKPIN members in all professional categories to help with this work.

## **GLILD Opportunity**

There is an exciting opportunity for us to work with our respiratory, radiology and pathology colleagues in developing consensus guidelines and patient materials for Granulomatous Lymphocytic Interstitial Lung Disease complicating primary immunodeficiency. This is a project supported by the British Lung Foundation and lead by John Hurst (UCL). Please read John's report and contact him directly if you are able to collaborate on the proposal or would like any more information.

#### Research

The refresh of the UKPIN website has also allowed the creation of an area dedicated to <u>research</u>. There are also interest groups dedicated to <u>research</u> and <u>GECIP</u>. We welcome a <u>report</u> from Sophie Hambleton on the current research initiatives focusing on the 100000 genome project.

### **News Stories**

Primary immunodeficiencies worldwide: an updated overview from Jeffrey Modell Centers Global Network Feb 08, 2016

Full Story

Developing an Immunology Specialist Supported European GP Network Jan 28, 2016

UKPIN has been made aware of a European initiative looking at improving awareness of PID amongst GPs.

Full Story

UKPIN and MDSAS Discuss Producing Annual Joint Reports **Nov 17, 2015** 

UKPIN and MDSAS have had discussions in relation to producing an annual joint reports on immunoglobulin usage across the UK.

Full Story

#### Opportunity to conference manage UKPIN 2017

The opportunity to tender to conference manage the UKPIN 2017 meeting in Brighton has arisen. Guidance is available by clicking <a href="here">here</a>. The closing date for application is **15th April 2016**.

#### **Events**

#### **ESID 2016**

The 17th Biennial Meeting of ESID will be held in Barcelona, Spain.

<u>Go comment!</u>

Read more...

#### Joint BSI and NVVI Congress 2016

Read more...

#### **UKPIN Immunology Forum 2017**

Save the Date - 7th to 8th December 2017 Brighton (immediately after the BSI conference)

# 3<sup>rd</sup>Biotest Immunology Forum at the Royal Society on 23rd and 24th June 2016 Read more...

Abstracts are welcome for the 3<sup>rd</sup> Biotest Immunology Forum from all members of the immunology community for the short talk session. These talks will be approximately 15 minutes and the synopsis should be sent to <a href="mmunology.forum@biotest.com">immunology.forum@biotest.com</a> by 27th April.