



United Kingdom Primary Immunodeficiency Network – Advancing Care in Primary Immunodeficiency

19/7/2019

Dear UKPIN Member and Stakeholder

Update on actions taken by UKPIN regarding the immunoglobulin supply issues related to the framework

The UKPIN Trustees would like to update you on the recent actions UKPIN has taken related to the immunoglobulin framework. As you will be aware UKPIN carried out a survey of membership in March 2019. The planned action following that survey was to write to the Secretary of State for Health. I attach that letter at the end of this communication. Disappointingly the response UKPIN received is detailed below:

Dear Dr Pereira Garcez,

Thank you for your correspondence of 10 June about immunoglobulin supply. I have been asked to reply.

I appreciate your concerns.

However, NHS England remains best placed to respond to your concerns. I can only advise that you continue to raise them with it directly. For ease of reference, the contact details are:

NHS England
PO Box 16738
Redditch B97 9PT

Tel: 0300 311 22 33

Email: england.contactus@nhs.net

I am sorry I cannot be more directly helpful.

UKPIN then followed the advice from the Secretary of State for Health and sent the communication to NHS England and received the below response – please do feel free to click on the link provided seemingly directing us to the elusive answers to the questions we had posed:

UKPIN | 34 Red Lion Square | London | WC1R 4SG | United Kingdom

+44 (0) 20 3019 5925 | www.ukpin.org.uk



United Kingdom Primary Immunodeficiency Network – Advancing Care in Primary Immunodeficiency

Dear Dr Pereira Garcez,

Thank you for your email to NHS England Customer Contact Centre received 18 June 2019.

In response to your email please find information on immunoglobulin supply via web link below.

<http://www.england.nhs.uk/?s=immunogloblin+supply>

I hope this information has helped.

UKPIN is currently working with new staff in NHS England to see if a response to our questions and a final lessons learned report will be forthcoming. If there is no progress we will enter into discussions with stakeholders about escalating action.

We will keep you informed.

Yours sincerely

A handwritten signature in blue ink that reads 'T Garcez'.

Tomaz Garcez
Chair UKPIN

The Rt Hon Matt Hancock MP
Secretary of State for Health

Sent by email only

10 June 2019

Dear Mr Hancock

I write to you on behalf of the membership of the United Kingdom Primary Immunodeficiency Network (UKPIN, a network of healthcare professionals involved in the care of patients with primary immunodeficiency), following a survey carried out in March 2019 regarding supply issues with normal human immunoglobulin (Ig). Ig is an essential medicine for patients with primary immunodeficiency (PID). There is no alternative. Ig is a pooled plasma product resulting from the pooling and processing of thousands of blood donor collections. Global demand for Ig has increased recently as clinical indications have increased. The only condition for which there is no alternative treatment remains PID. Due to the global demand change there have been changes in price also globally. NHS England has agreed prices for Ig through the national framework process. This process contributed to a crisis in supply of Ig over 2018 / 2019. The survey carried out by UKPIN was aimed at exploring the impact and communication of this crisis. UKPIN had also asked NHS England to complete a lessons learned exercise in 2018, which was carried out as a workshop in June 2018. To this date the lessons learned by NHS England have not been agreed and circulated to the stakeholders. Similarly NHS England responded to a letter written by the relevant societies in September / October 2018 but the response has still not been approved by NHS England for release.

Please see attached copy of the survey information, attachments sent with the survey and survey report.

UKPIN asks for the following:

1. NHS England provides assurance that the Ig supply for PID patients is secured and that there is no ongoing disruption to their treatment
2. PID patients are placed within the highest priority ranking for Ig supply, both intravenous and subcutaneous, within the recently initiated review of the demand management plan for immunoglobulin
3. NHS England works with UKPIN and the other societies to identify methods to improve communication with relevant stakeholders
4. NHS England produces a signed off lessons learned document that provides reassurance that the issues of the last framework are not repeated in the future
5. NHS England releases a signed off response to the societies

We would like to see urgent action on this and the two latter actions should be completed within 4 weeks.

Yours sincerely



Tomaz Garcez
Chairman on behalf of UKPIN



Sofia Grigoriadou
Clinical Secretary on behalf of British Society for Immunology

Cc – James Palmer, Philippa Turner, Rob Coster, Siraj Misbah

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