

1st May, 2018



Dear PID Patient,

You may have heard rumours that there is a worldwide shortage of immunoglobulin replacement therapy. The purpose of this Information Document is to give you a better understanding of what is actually happening and how the NHS in England/Scotland and your Clinical Immunology Teams are dealing with this.

The most important thing for us to say is that there is no need for people living with a Primary Immune Deficiency whose consultant Clinical Immunologist has stated that they need replacement immunoglobulin therapy (IgG) to worry. This is because the specialist teams in NHS England/Scotland who buy immunoglobulin replacement therapy, have worked very hard to make certain that there will be enough replacement immunoglobulin therapy for those of us with the type of Primary Immune Deficiencies who need this in order to sustain us. This is called “ring fencing” supplies of IgG for us and they have done this because they recognise how important our IgG infusions are for our well-being.

However, whilst there is enough IgG for us, it is possible that some of us may have to change the brand of IgG, or the method by which we have our infusions. Again, please do not worry. If this is going to affect you or the PID patient that you care for, your Clinical Immunology Team will either have already contacted you or will be contacting you in the next month to let you know that they will be changing you to a different product and/or method of infusing. Your clinical immunology teams will give you full support and talk with you about any concerns that you may have. Patient safety and getting things set up in the right way for you is the most important thing for your teams and the NHS in England/Scotland.

The pharmaceutical companies who produce our IgG therapy are also working very hard to ensure that our treatment continues as smoothly as possible given the issues that we are facing. Some companies have managed to make more of their IgG therapy available to NHS England/Scotland. The manufacturers of one IV product, who have had to very reluctantly withdraw this product from the UK, are making more of their subcutaneous IgG products available. Recognising that switching patients from one product/method puts a lot of pressure on our already overworked clinical immunology teams, this company is following in the footsteps of others and

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is going to make available their considerably increased home care service, which will deliver product and all of the accessories we need to infuse to patient's homes (or another address that the patient may chose). They are also providing nurses, who are receiving training from some of our most experienced Immunology Clinical Nurse Specialists so that they can train PID patients who have to change from I.V. Infusions to Subcutaneous Infusions. They will also be supplying the pumps needed for these infusions. All of these services are being supplied by the company free of charge to NHS England/Scotland and this agreement is initially in place until 4th April 2020.

Please remember that UKPIPS will be here to continue to support our community members by telephone, email and our closed Facebook Groups. We continue to work very closely with NHS England/Scotland, all of the pharmaceutical companies who provide products that PID patients use; and other relevant charities who also use immunoglobulin products, to ensure that we can give you the support that you need.

If you want to learn more about the supply of Immunoglobulin Therapy worldwide, please contact UKPIPS. By telephone: 01386 421228. By email: admin@ukpips.org. or through our website: www.ukpips.org.uk

If you want to know more about how any of this may affect you or the PID patient that you care for, please contact your clinical immunology teams by the method you usually use.

Immunoglobulin Replacement Therapy is our Liquid Gold. Thank you to all of those who work so hard to make it available to us.

Yours sincerely



Liz Macartney
UKPIPS Chair of Trustees



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