

PE1408/QQ

Petitioner submission of 21 February 2018

The Scottish government recently contacted the Haematology Short Life Working Group to request that they arrange a meeting with me to discuss the matters raised, and this meeting has now taken place. I found it to be a very positive experience and I was given an opportunity to inform them of all the issues that I feel are preventing many patients from being adequately treated.

One particular problem that became clear is that there is no particular group in existence to which to direct problems which patients with PA, and other similar conditions, face in their efforts to be treated and this is perhaps why it has proven so difficult to arrange direct dialogue between myself and the NHS. I understand that the Haematology Working Group are already intending to submit an application for the establishment of an Haematology Diagnostic Network in the near future and this, if approved, should provide a dedicated facility to gather together all the various aspects and challenges of their speciality.

In the meantime, it has been confirmed that they will continue to liaise with me and I am very appreciative of that opportunity.

Two other issues I raised which are outwith their control are:

1. To have injectable hydroxocobalamin licenced for both intramuscular and subcutaneous administration, as is the case with some brands of hydroxocobalamin, one of which is already being prescribed to patients in the UK.
2. To remove the 'prescription only' requirement and allow injectable B12 to be available to buy over the counter in pharmacies. This is what already happens in some EU countries, France, Germany and Spain for sure. This would be an appropriate and cost-effective way for patients to take control of their own treatment and relieve the burden on GP surgeries which have to facilitate nurse appointments to administer these injections. Once patients had received their initial loading injections, and been instructed in how to inject themselves subcutaneously, those who felt comfortable doing so could then administer their own maintenance therapy, at whatever level they personally required.

I would therefore be grateful if I could be informed of how I may take both these issues forward with the appropriate departments.