

29<sup>th</sup> November 2012

Mr. David Stewart MSP  
Convener  
Public Petitions Committee  
The Scottish Parliament  
Edinburgh  
EH99 1SP

Dear Mr. Stewart

**Re: Petition PE1408**

I thank you for the recent update on the above petition and the invitation to submit our comments to the committee.

Since there are no further developments likely to take place until after the BCSH publishes its updated guidelines on the treatment of B12 and Folate Deficiencies in 2013, we would again like to draw your attention to the fact that the PA Society are still waiting to be asked by the BCSH for our involvement in this process and, as indicated in the official parliamentary report of the petitions committee meeting of 18<sup>th</sup> September, you advised the following:

*“We were given assurances at previous meetings that the Pernicious Anaemia Society would be fully consulted and involved in discussions with the British committee for standards in haematology. According to the letter of 25 August, the Pernicious Anaemia Society has not been consulted, despite the fact that the chair of the society wrote to seek involvement in the discussions on how that committee intends to proceed.”*

We feel it is crucial that we are involved in the formulation of new guidelines as these are what are having the greatest negative impact on how patients are being treated.

We would also like to draw your attention to developments with the Active-B12 test referred to in previous correspondence. The PA Society has now heard from at least six members who have had this test done. Although the patients have to pay for the test themselves and be able to attend the London hospital concerned at their own cost, at the present time they need a referral letter from their GP. Some members have informed us that their GP refused to supply them with a referral letter so they were unable to have the test done in order to hopefully prove a functional deficiency. Of the six who were able to have the test, four had a functional B12 deficiency but only two were able to persuade their GP to commence treatment based on the test result. These results would seem to prove that this test has the potential to indicate a functional deficiency in the presence of a normal serum level. It also reveals that GPs are still prepared to ignore the result of this new test or refuse to enable their patient to access the test in the first place,

Yours sincerely

Andrea MacArthur