

## PE1408/HH

Petitioner Submission of 12 September 2016

I am aware that, following the last consideration of this petition in July 2016, the Scottish Government were asked for their comments on certain issues. Their response has now been received but does not tell us anything that we didn't already know.

It was already known to the committee and myself that the SHS could not do what was asked of them and I am dismayed that there have been no suggestions as to who else could prepare a summary document. Surely it can't just be left hanging – there must be some health department qualified for the task. What about the British Society of Haematology (BSH) themselves? However, even then that would still leave us with my other questions unanswered as they specifically relate to parts of the full guidelines issued by that very society. Why have they not been asked directly for their response to the points I raised, since they question the validity of certain aspects of their own guidelines?

As you can see, I am becoming extremely frustrated as we appear to be going around in circles due to no one wanting to answer very relevant and important questions about the present understanding and treatment of B12 Deficiency.

It is equally frustrating to be told that any problems that patients encounter trying to be adequately treated are '*a clinical issue*' and '*a matter for discussion and agreement between doctor and patient.*' Sadly, there is rarely agreement when patients ask for a tailored treatment plan based on their needs. Again, it cannot just be left at that as patients are being let down by their doctors out-dated understanding of the best way to treat their patient. This is not necessarily the fault of the individual doctor but rather is due to them simply following the current inadequate treatment protocol and this brings us back to the whole point of this petition – and that is to recognise and admit that there is a serious problem here, and do whatever can be done to ensure doctors have the best advice available to them so they can offer their patients effective personalised treatment.

This petition has been in force for almost five years now and all that has been achieved is to have the new guidelines drawn up. This is good in itself, but what is the point if no one has to adhere to them, or is even aware of them, and the guidelines themselves are not open to constructive criticism? The problems I have highlighted are not trivial, they make sense logically and medically speaking, and seriously affect patients' hopes of recovery and stability of health. In many cases, it rules out treatment altogether, despite the patient already being in an advanced state of decline.

I ask you, please, to continue to seek answers to the problems I have highlighted, and to the questions I have repeatedly asked,

Yours sincerely,  
Andrea MacArthur