PE1408/LL
Petitioner - Mrs Andrea MacArthur of 27 February 2017

I see from the Scottish Government's response of 15th February that, despite them quoting a previous comment confirming that the format of the full guideline was not suitable for use in the practice setting, clinicians are still being expected to refer to it for guidance. It is either suitable or unsuitable for clinical use - and had previously been confirmed to be unsuitable. Nothing has changed to make it suitable, so why is it now being deemed so?

As I already said in my previous submission, GPs will not, and cannot, be expected to read through such a lengthy article in a practice setting, even if they had the time to do so. What makes it even more frustrating is that the guideline had successfully been summarised by the Scottish Haematology Society (SHS) before they later withdrew from the process, and the reason I suspect they did so was because I challenged the same particular aspects of the summarised document, which had been carried over from the original full guideline. Considering I have been challenging these same issues for the last five years, it would have been ridiculous to then accept them being incorporated into a new summarised document intended for clinical use.

I have a certain sympathy for the SHS as their summary document was well constructed, however, perhaps they realised that the points I raised were legitimate but they were unable to consider amending their advice without having to challenge the British Society for Haematology (BSH), which they understandably may not want to do. This would seem to be hinted at in their comments of 22nd March 2016:

'The society does not have the size or resources of its much larger, British counterpart - The British Society for Haematology (BSH). The draft guidelines the SHS produced were hoped to be of use'

However, the very considered responses we have received from the petitioners in response to the draft guideline indicate the limitations our small society has in trying to produce specific Scottish guidelines.'

'With regret the SHS must therefore withdraw from this process.'

Since the very beginning of this petition process, my main two issues have been:

1. **The refusal to treat patients symptomatically, or believe that their symptoms have the potential to respond to a greater frequency of B12 injections, or even that these symptoms are necessarily related to their B12 deficiency. It seems GPs would rather medicate these patients with other costly, inappropriate and ineffective medicines than simply increase their level of injections. This does not make any sense to me whatsoever, especially when I received the most**

effective treatment from my own GP and was given access to a symptomatic level of injectable B12.

2. **The refusal to heed the results of the Gastric Parietal Cell Antibody blood test, and interpret it appropriately. As I mentioned yet again in my previous response:**

The BSH Guideline states the following:

'Gastric parietal cell (GPC) antibodies have a low specificity for the presence of pernicious anaemia as, despite being positive in 80% of pernicious anaemia subjects, they are also positive in 10% of normal individuals. Positive GPC antibodies may cause gastric acid achlorhydria and progression to pernicious anaemia may occur. However, a positive GPC antibody test is not definitive for pernicious anaemia.

Recommendation: Anti-GPC antibody testing for diagnosing pernicious anaemia is not recommended'

Yet, the following article[1] from the Food & Agriculture Organisation of the UN (FAO) has this to say:

'Malabsorption of vitamin B12 can occur at several points during digestion. By far the most important condition resulting in vitamin B12 malabsorption is the auto-immune disease called pernicious anaemia (PA). In most cases of PA, antibodies are produced against the parietal cells causing them to atrophy, lose their ability to produce intrinsic factor, and secrete hydrochloric acid.'

It is widely known in the medical profession that the stomach's parietal cells produce both hydrochloric acid and a protein called Intrinsic Factor, both of which are required for nutrient absorption and, in particular, vitamin B12. If these cells atrophy, it is obvious even to non-medical people that it must therefore result in PA.

These two issues have not been addressed to date, and I can't understand why no one from the medical profession will even acknowledge them, let alone answer them for me. It is therefore appropriate that the BSH be asked to answer them, since their guideline on B12 Deficiency includes advice based upon their present understanding of this particular test. As regards frequency of treatment, I know I will simply be told that this is a decision for the individual doctor but that does not address the situation that many patients face – this being that they are either not being diagnosed at all despite all the relevant symptoms, or they are being left with an inadequate level of treatment and continuing to suffer further decline. They may not even be diagnosed at all due to the GP following the advice given on the interpretation of the Gastric Parietal Cell blood test. It should therefore be noted that my question about this particular test is not only crucial for

[1] http://www.fao.org/docrep/004/y2809e/y2809e0b.htm

undiagnosed patients who test positive for PC antibodies but it is also a direct enquiry about the accuracy of the general interpretation of the test itself.

I feel that, after spending six years as a moderator on the PA Society's website forum, followed by a further two years being part of a separate 14,000+ strong support group, and having also experienced the severe symptoms of an extreme deficiency myself, I have a good understanding of the widespread problems patients with Vitamin B12 deficiency face on a daily basis. I have always been determined to conduct this petition in a responsible manner, and be respectful of the medical profession of whose services, on the whole, I am a grateful recipient, but I am extremely disappointed that my perfectly reasonable and legitimate questions are being ignored. Why should the NHS not want to treat its patients effectively? It would obviously greatly benefit the patients themselves but would also alleviate the burden of them continually presenting themselves to their GPs due to other areas of their health breaking down, and potentially avoid the need for other expensive medicines and procedures.

I make my plea, yet again, that my comments be put to the medical profession for their considered response.

Yours faithfully,