

Scottish Parliament - Petition: PE 1408  
Petitioner - Mrs Andrea MacArthur

6th October 2014

I note that the petition is due to be considered again later this month and now submit my latest response.

In my previous response in June 2014, you will see specific mention was made of the fact that no recommendation has been made for the large group of patients who need more frequent injections than are routinely given and this situation has not been acknowledged by the BCSH despite it forming the focal point of the petition. I cannot afford to let this go unchallenged. This is a serious issue for patients and is making the difference between them having any quality of life or continuing to deteriorate despite standard maintenance B12 injections. I cannot emphasise this enough – it is not, as celebrity use of B12 would suggest, that it is merely a quick pick-me-up – an effective level of injections is crucial for those who, for perhaps unknown reasons, cannot absorb their own B12. Why is there such resistance to treating patients with whatever level of B12 they personally need? It is one of the safest medicines available on the NHS yet there is such widespread opposition to allowing patients what they need to function, with a tendency to regard patient reports of improvement as being a *'placebo effect.'* Even supposing this was true (which it isn't!), is it not still preferable to administer a harmless vitamin than any of the other serious medicines routinely offered instead? Surely, the purpose of any treatment is to address symptoms and enable the patient to feel better and if that occurs on frequent B12 then the desired outcome has been achieved and has to be preferable to instead prescribing medicines with serious side effects and complications which, at best, merely mask the problem rather than address it. B12 is also considerably cheaper than most of those other medicines (one ampoule at present costs the NHS just 73p). In other words, there is no valid reason to justify denying adequate B12 to patients, not even the fact that it requires to be injected as patients can be taught to self-inject as happens with diabetic patients. I appreciate that some patients may not feel able to inject into muscle (IM) but one particular brand of injectable hydroxocobalamin<sup>1</sup> advises both intramuscular and subcutaneous (SC) injection routes as being acceptable and perhaps it is time for the NHS to seriously look at this option. Indeed, I switched from IM to SC myself once the injection sites began to become resistant from continued use and found this method just as effective.

Alarming, it has also recently become increasingly more common to hear from patients whose GPs are continuing to monitor their B12 levels and withdraw treatment when the serum level is elevated, which is inevitable once on injections. The new BCSH Guidelines specifically state, "*No further testing of cobalamin levels is required.*"<sup>2</sup> These patients typically then significantly worsen yet cannot get their injections reinstated. Even pregnant women have reported their injections being stopped, purely because they are pregnant – the very time they need more than ever to protect their babies' development. These new guidelines also include the following advice:

"The BNF advises that patients presenting with neurological symptoms should receive 1000 µg i.m. on alternative days until there is no further improvement. However, the GWG recommends a pragmatic approach in patients with neurological symptoms by reviewing the need for continuation of alternative day therapy after three weeks of treatment."

Sadly, what I feared has already happened twice in this last week alone – two people have reported to the support group in which I am involved that an haematologist authorised continued loading injection therapy but stated that it should be reviewed at 3 weeks. The loading injections

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on both occasions were then withdrawn after this period as the patients hadn't yet shown a positive response to them, even although this is a fairly normal finding in many of our members, for whom it is often several months before improvement is felt.

We are also seeing an increasing tendency for doctors to disregard a positive test for Gastric Parietal Cell Antibodies and deny treatment on the basis of it. The BCSH Guidelines state that, *"despite being positive in 80% of pernicious anaemia subjects, they are also positive in 10% of normal individuals."* It is rather puzzling why many doctors prefer to regard their patient as being in the 10% category rather than the 80% one – especially when they already have the expected symptoms of advanced PA.

I really do appreciate the positive changes in the new guidelines as they at last admit that the serum test has its failings and recommend taking the clinical picture into account as much as laboratory data. This is a massive step forward. However, this will be of no value if patients continue to have their injection frequency reduced or stopped or are expected to survive on a level which is insufficient to enable improvement or prevent further deterioration. I fully understand that more research has to be done to try to discover why some patients need more frequent injections than others. Sadly though, in the meantime people are suffering badly from not being able to obtain an adequate level of treatment for their particular need. Surely, it is not right to withhold treatment until medical research catches up. Since B12 has no known issues of toxicity at high levels, can there not be information given to all GPs and clinicians to begin treating patients on a symptomatic basis and allowing the patient to decide what level of B12 is needed to keep their symptoms at bay? This is no more than happens with other conditions as no two people respond exactly the same whatever the medical condition happens to be.

Perhaps once the above concerns have been effectively addressed, I can be advised when we can expect the current BNF guidelines to be updated accordingly.

Yours faithfully,

Andrea MacArthur

1. [http://www.bcsghguidelines.com/documents/BCSH\\_Cobalamin\\_and\\_Folate\\_Guidelines\\_\(2\).docx.pdf](http://www.bcsghguidelines.com/documents/BCSH_Cobalamin_and_Folate_Guidelines_(2).docx.pdf)
2. [http://www.mycare.de/medias/sys\\_master/8452750605353408.pdf](http://www.mycare.de/medias/sys_master/8452750605353408.pdf) "VITAMIN B12 DEPOT Injektipas® 1500 micrograms is usually administered intramuscularly. It can also be given intravenously or subcutaneously.