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Dear Kayleigh

Re Petition **P-04-57115.02.22**

Thank you for your email of the 26th February.

I make the following observations and responses.

Just over 10% of members of the Pernicious Anaemia Society use a form of B₁₂ (methylcobalamin) which is not licensed for use in Europe or North America. This form of B₁₂ has been shown to repair damage to the Myelin Sheath which is the biggest cause of nerve damage in patients.

48% of patients surveyed by the PA Society were unhappy with their treatment!

There is now a growing consensus that some patients need more frequent injections than others.

'Finally, many clinicians and patients are aware of considerable individual variability in the response to treatment with vitamin B12. Patients often continue to experience mild neurological symptoms such as poor memory, impaired concentration and fatigue even after adequate B12 replacement. The reason for this is currently unknown, but future research into the interplay between polymorphisms in

transcobalamin and its cell membrane receptor might offer some explanation for this curious phenomenon'.ⁱⁱ

There are many hypotheses for this and the PA Society is working with two teams of clinical researchers to discover just why this is so – it could be due to gut flora invading the small intestine (ileum) or it could be due to inherited non-functioning cell receptors. This research is still being undertaken.

The comments about patients self-injecting without receiving any instruction, without using sterile syringes or lockable sharps' bins is of huge concern to the Pa Society which is why we would prefer this practice to be overseen by trained and qualified medical professionals and not be an 'underground' practice that it currently is. The number of patients using 'private' doctors who are more than willing to inject patients according to their needs (a new 'clinic' has just opened in Chester with an introductory price of £28 per injection) or are sourcing injections from more dubious places such as hair and beauty therapists (B₁₂ injections are increasingly popular among celebrities such as Simon Cowell, Rita Ora et al) or from online 'pharmacies'. The more savvy of self-injectors simply travel to continental Europe where the injections are readily available at pharmacies as 'over the counter' medicine and source single use syringes, pre-injection wipes and lockable sharps bins from needle exchanges in the UK. That's why it would be beneficial for patients who need more frequent injections to receive them from their medical supervisors rather than turning to unregulated and unlicensed sources.

The use of oral supplementation is one that is practiced by some of the members of the PA Society but it is seen as unsatisfactory for most patients for two reasons; firstly most of the oral preparations are formed around cyanide (cyanocobalamin) and secondly because the evidence is flimsy – for example the Cochrane Review conducted a few years ago was based on a very narrow patient group of a particular age group and gender. The PA Society has a policy on the use of Cyanocobalamin tablets that I will gladly let you have a copy of if you wish.

The market for more frequent supplementation has responded by producing some very ingenious treatments including sub-lingual spray (methylcobalamin) which is readily available and which is now used instead of injections by many of our members as they can get a daily 'feed' of methylcobalamin rather than having to experience the wide range of symptoms in the run-up to their injection. Others include sublingual lozenges, nasal sprays, skin patches and even suppositories. None of these products has been evaluated as to their effectiveness in reducing the patients' symptoms which is the only way in which any assessment could be carried out – simply raising serum B₁₂ levels doesn't always work.

I am not in a position to offer any guidance to your medical professionals or elected representatives. I am not a doctor and do not pretend to know more about the treatment of Pernicious Anaemia than do medical professionals. What I am in a position to say, and what I do know is that the current 'one size fits all' treatment is not suitable for a great many of our members. Often it is the case that it is not the patient who feels that he or she is beginning to experience what can be the debilitating symptoms of B₁₂ deficiency – often it is work colleagues, family and friends. No placebo trials have been carried out and published in this area and so any reference to patients experiencing a 'placebo effect' are simply conjecture and is not based on any scientific foundation. And it is useful to remember that many of our members manage perfectly well on an injection every three months but that doesn't stop the continual telephone calls, letters and emails from patients who need much more frequent replacement therapy.

I do hope that this will help the committee to see that this whole issue of treating PA needs to be reviewed by a team of professionals.

Thank you for your help in this matter. Should you require any further information please don't hesitate to contact me.

Yours sincerely

Martyn Hooper

ⁱ Hooper et al; Patient journeys: diagnosis and treatment of pernicious anaemia; British Journal of Nursing, 2014, Vol 23, No 7

ⁱⁱ McCaddon A; Vitamin B12 in neurology and ageing; Clinical and genetic aspects; Biochimie 95 (2013) 1066e1076