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Scottish Registered Charity no. SC046066

Saturday 21 March 2020

Dear Sir/Madam

URGENT LIFE-SAVING VITAMIN B12 TREATMENT BEING DENIED

I write to you as President of The B12 Society, a Scottish registered charity with over 14,000 members in our online support group. We provide education on vitamin B12 malabsorption (deficiency) and pernicious anaemia (autoimmune condition), and give support to sufferers across the United Kingdom and overseas. These conditions result in an inability to absorb B12 from food; if left untreated they can cause debilitating systemic symptoms, including the potential for irreversible neurological damage. The standard of care for both these conditions is lifelong B12 injections. If left untreated in the long term, B12 deficiency and pernicious anaemia will result in death.

I was greatly alarmed to hear from our members that some general practice surgeries in Scotland and the wider UK are denying B12 deficiency and pernicious anaemia patients their life-saving B12 injections due to the COVID-19 crisis. Apparently these surgeries do not consider B12 injections to be an essential medicine.

Although I fully understand the resource restrictions being caused by the current crisis, the consequences of such action will undoubtedly put many patients at unnecessary risk. I am therefore asking you to help us with the following points:

1. Ensure those surgeries reinstate these life-saving injections as a matter of urgency

or

2.Ensure those surgeries instruct their patients on how to administer their own injections and provide them with the supplies to do so

Please understand that these injections, unlike drugs such as insulin and methotrexate (among other commonly self-administered injections), are nontoxic and there is no upper limit of intake [1]; it is a water-soluble vitamin and any excess will be excreted in the urine. Hence there is no concern for overdose when a patient is self-administering B12 injections.

To help you understand the urgency of this situation, I list below some important information:

- Hydroxocobalamin is the form of B12 used for injection in the United Kingdom. The World Health Organisation has listed this form of B12 as an "ESSENTIAL MEDICINE". This means that, at all times, there must be a supply of this medicine available for those people who require it as essential to life [2].
- The British Society for Haematology state that, once diagnosed with pernicious anaemia or other B12 deficiency due to malabsorption, a patient should receive life-long hydroxocobalamin treatment [3]
- Every doctor in the UK receives a copy of the British National Formulary (BNF) prescribing guidelines. Those guidelines state the dose and frequency of hydroxocobalamin injections [4]. Please note that cyanocobalamin tablets, which are being offered to some patients as an alternative to injections, are only recommended in the BNF for treatment of dietary B12 deficiency [5]. Tablets are not proven to be an adequate substitute for injections in terms of patient outcomes [6].

• The NHS website clearly states "Although many of the symptoms improve with treatment, some problems caused by the condition can be irreversible if left untreated. The longer the condition goes untreated, the higher the chance of permanent damage." [7]

No one knows how long the COVID-19 crisis will last, but it is essential that all patients with B12 deficiency and pernicious anaemia receive their injections in order to prevent any deterioration in their health. Inadequate treatment will not only cause a relapse of symptoms, but will make patients more susceptible to contracting infections including COVID-19; this will create further need for medical attention and hospitalisation and will thus place further strain on an already stretched NHS.

I will be most appreciative of whatever assistance you may be able to provide, and I look forward to hearing from you as soon as possible.

Yours faithfully,

Heather Hardie

President - The B12 Society

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References

[1] European Food Safety Authority, 2006. Tolerable Upper Intake Levels for Vitamins and Minerals. Available from:

http://www.efsa.europa.eu/sites/default/files/efsa_rep/blobserver_assets/ndatolerableuil.pdf (refer to page 48)

[2] World Health Organization, 2019. Model List of Essential Medicines, 21st list. Available from: https://apps.who.int/iris/bitstream/handle/10665/325771/WHO-MVP-EMP-IAU-2019.06-eng.pdf?ua=1 (refer to page 34)

[3] Devalia V, Hamilton MS, Molloy AM on behalf of the British Committee for Standards in Haematology, 2014. Guidelines for the Diagnosis and Treatment of Cobalamin and Folate Disorders. British Journal of Haematology 166: 496–513. Available from: https://onlinelibrary.wiley.com/doi/epdf/10.1111/bjh.12959

[4] British National Formulary. Hydroxocobalamin. Available from: https://bnf.nice.org.uk/drug/hydroxocobalamin.html

[5] British National Formulary. Cyanocobalamin. Available from: https://bnf.nice.org.uk/drug/cyanocobalamin.html

[6] Wang H, Li L, Qin L, Song Y, Vidal-Alaball J, Liu T, 2018. Oral vitamin B versus intramuscular vitamin B for vitamin B deficiency. Cochrane Database of Systematic Reviews, Issue 3. Art. No.: CD004655. Available from:

https://www.cochrane.org/CD004655/ENDOC oral-vitamin-b12-compared-intramuscular-vitamin-b12-vitamin-b12-deficiency

[7] NHS. Symptoms – Vitamin B12 or Folate Deficiency Anaemia. Available from: https://www.nhs.uk/conditions/vitamin-b12-or-folate-deficiency-anaemia/symptoms/