

PETITION'S COMMITTEE BRIEFING

BACKGROUND

- Vitamin B₁₂ Deficiency is a worldwide problem.
- In the UK it is estimated that nearly 6 million of the general population are deficient in this essential nutrient.
- The biggest cause of B₁₂ Deficiency is Pernicious Anaemia.
- Patients who have Pernicious Anaemia are unable to absorb Vitamin B₁₂ from food (animal products).
- Vitamin B₁₂ is needed to produce healthy red blood cells that transport oxygen around the body.

WHAT'S THE PROBLEM?

Problems with the symptoms:

- The symptoms are insidious and can easily be associated with advancing age – they are often ignored and they include: continual tiredness, lethargy, shortage of breath, changes in behaviour, mood swings, irrational behaviour, memory loss, difficulty with finding the right words for everyday things, desire for solitude, aversion to bright lights and noisy environments, digestive problems, sudden unaccountable bouts of diarrhoea.

Problems with the diagnosis:

- The current test used to determine B₁₂ status in patients gives false high results in up to 35% of cases. This leads to misdiagnosis.
- **The British Committee for Standards in Haematology recently suggested that doctors pay more attention to the patient's symptoms than to the currently used test to determine any deficiency as the test is seriously flawed and not fit for purpose.**

- Common misdiagnoses include: Chronic Fatigue Syndrome, Depression, Hypochondria, Multiple Sclerosis (left undiagnosed and untreated PA leads to severe and irreversible nerve damage).
- 21% of our members waited over two years for a correct diagnosis.
- 19% waited over five years.
- 14% waited over ten years to be told the reason for their symptoms.

Problems with the treatment:

- The biggest cause of complaint by members of the PA Society is about their treatment.
- The treatment is extremely cheap (less than 40p) and extremely safe.
- For a great many UK patients the usually prescribed replacement therapy injection once every three months is woefully inadequate. Often it is the patient's family, friends or work colleagues that notice a change in personality or workplace performance as the time from the last treatment progresses.
- In the 1960's replacement therapy injections were prescribed every month, in 1974 that was changed to every two months and then to every three months in 1984. We are unaware of any research that these changes were based on.
- While some doctors will allow more frequent injections most refuse which means the patient has two alternatives. Either they suffer the return of their symptoms which impacts on work and family life, or they obtain more B₁₂ from alternative sources including internet 'pharmacies', beauty therapists, private clinics or travel to mainland Europe where the injections are available from pharmacies – in the UK the injections are available only on prescription.
- There are other ways in which replacement therapy B₁₂ can be delivered including trans-dermal patches, sub-lingual sprays, sub-lingual lozenges, nasal sprays and large dose oral tablets – none of which are available in the NHS. With the exception of the large dose oral tablets none of these alternative delivery methods has been evaluated.

- Left untreated Pernicious Anaemia leads to a slow inevitable death.

WHAT WE WANT FROM YOU

- We want you to be aware of how the problems with the diagnosis and treatment of Pernicious Anaemia could be affecting not only your constituents but also your families and friends.
- We want you to use your influence to help us bring about our main objective.
- We want you to suggest ways in which we can get the issues outlined above addressed.

WHAT WE WANT

Our main objective is to procure a thorough review of the way in which Pernicious Anaemia is diagnosed and treated by a suitably qualified and experienced individual or group.

Thank you for taking the time to read this briefing.

Further information from:

Martyn Hooper – 07545897608/ 01656769717

www.pernicious-anaemia-society.org

The Pernicious Anaemia Society is based in south Wales and has nearly 10,000 members from around the world. It is a registered charity, run entirely by volunteers. Our youngest member is 18 months old and the oldest has just celebrated her 100th birthday.