

## BRIEFING

The Pernicious Anaemia Society is the only registered charity in the world that offers Information and Support to patients with Pernicious Anaemia and their families and friends. Pernicious Anaemia means the patient is unable to absorb Vitamin B<sub>12</sub> from food which means he or she is unable to produce healthy red blood cells and this leads to a wide range of symptoms including shortage of breath, extreme tiredness, memory loss, confusion and irrational behaviour.

The society has been successful in bringing to the attention of decision makers in the world of health and medicine that there are serious problems with the way in which Pernicious Anaemia is diagnosed. Misdiagnosis is rife:

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.

Common misdiagnoses include: Chronic Fatigue Syndrome, Depression, Hypochondria, Multiple Sclerosis (left undiagnosed and untreated PA leads to severe and irreversible nerve damage), Psychosis.

Thankfully, following a series of meetings with officials from the Dept. of Health, new Guidelines on treating B<sub>12</sub> Deficiency and Folate were produced in May 2014. The new Guidelines highlight the problems with the current test used to diagnose B<sub>12</sub> Status in patients and whether that deficiency is caused by Pernicious Anaemia.

Now we want to highlight the problems with patients being treated for Pernicious Anaemia. Treatment involves replacement therapy injections of vitamin B<sub>12</sub> which is extremely cheap and extremely safe. This is what we know:

Injections were prescribed every month in the 1960's, this was changed to every two months in 1974 and then to every three months in 1984.

**By far the biggest cause of complaint by members is that they cannot get a treatment regimen based on their needs and often they have to suffer for two months before getting their injection.** When they experience a return of the symptoms patients suffer problems in the workplace and at home.

Patients who need more frequent injections than others are routinely refused these by their GP. Most doctors will believe that the patient is 'imagining' the return of the symptoms and will offer antidepressants. Often it is the patient's family and friend who will have noticed a return of the patient's symptoms long before their next injection is due.

Often the patient's blood will show 'adequate' levels of B<sub>12</sub> in their blood which endorses their opinion. But we now know that there are different types of B<sub>12</sub> (active and inactive) that the current test does not distinguish between.

Patients who need more frequent injections are then forced to explore a variety of solutions:

They can pay for injections in the private sector ('celebrities' do this) or turn to others who provide the injections including hairdressers and fitness instructors.

They buy forms of B<sub>12</sub> injections from the internet (totally advised against by the PA Society)

They buy nasal sprays, skin patches, sub-lingual drops and sprays from various sources including high street health shops (none of these alternative forms have been evaluated)

They travel to mainland Europe where the injections are available 'over the counter' at pharmacies in most countries – they then inject themselves without receiving any training and without using pre-injection wipes or lockable sharps bins

They undergo Intravenous Infusions where a bag full of B<sub>12</sub> is drip fed into a vein (a favourite of Simon Callow et al)

Or

They do nothing and suffer until their next injection is due.

#### WHAT DO WE WANT

We want someone who is professionally qualified to carry out a thorough Review of the way in which patients who have Pernicious Anaemia are treated and hopefully introduce a treatment regimen that is based on the individual needs of the patients.

Note – the PA Society is currently working with three teams of clinical researchers in four different universities to try to understand why some patients need more frequent injections than others.

The Pernicious Anaemia Society has offered a Membership Package for the past four years. We now have just a few short of 10,000 members from all parts of the world. We are based in Bridgend south Wales.

We are run entirely by volunteers.

B<sub>12</sub> Deficiency could be a problem for between 40-50% of the general population.

The symptoms of B<sub>12</sub> Deficiency are insidious and are often associated with advancing age.

The youngest member of the PA Society is 18 months', our oldest member has just celebrated her 100<sup>th</sup> Birthday.

ENDS

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