

SCOTTISH PARLIAMENT PUBLIC PETITION PE01463 on EFFECTIVE THYROID and ADRENAL TESTING, DIAGNOSIS and TREATMENT

In response to MHRA letter of 5th August, we wholeheartedly agree with the MHRA that it would be beneficial to have more than one source of Liothyronine in the UK. We must never have a repeat of the disastrous and dangerous situation many of us found ourselves in earlier this year, when patients' well-being and, indeed, their lives were put in jeopardy.

Unlicensed alternatives were sourced by MHRA but many chemists were without stock for several weeks. Numerous patients, who were down to single numbers of this life-saving medication, had to source it from abroad themselves. Worryingly, the Liothyronine shortage was ongoing for at least a month before MHRA took action. Some doctors sourced American Liothyronine (Paddock brand) at a cost of £374 per 100 x 5mcg¹ tablets. If the patient is taking 4 doses daily, a common dosage, the monthly cost to the NHS is extremely high. Some doctors are not prepared to order at this cost and advise patients to cut their tablets into four pieces. However, this makes it impossible to dose accurately.

In this instance, the MHRA sourced safe unlicensed thyroid medication as an emergency. These are the same safe, unlicensed medicines that many patients have to resort to buying online when they are refused T3 by their doctors. Therefore, it stands to reason that unlicensed NATURAL desiccated THYROID (NDT) medication can indeed be sourced for those patients whose biochemistry favours that particular treatment. This would enable them to stay in good health. Instead, NDT patients are being told they will not be monitored unless they go back to the inadequate Levothyroxine treatment. Many patients on T3 (Liothyronine) cannot get the laboratories to test their FT3 levels even if their GPs request it, regardless of how crucial it is for that particular patient's good health.

Demand for these medications will rise dramatically if our petition is successful. Currently, our doctors have neither the awareness nor the appropriate testing facilities available to them. And, because non-conversion (ie T4 to active T3) is not recognised at GP level, patients are not reaching the appropriate specialists. How then, is it possible for anyone to KNOW how many people need active T3 hormone? And how can anyone legitimately deny them this life-saving medication?

Recognising and identifying signs and symptoms by looking deeper, listening carefully and testing correctly will soon prove that numerous patients suffer from this condition. An early diagnosis will allow our GPs to prescribe individualised treatment in the appropriate combination of T4/T3 or Natural Desiccated Thyroid medication rather than the current one-size-fits-all practice of prescribing T4 only.

This "one-size fits all" approach prevents our doctors from honouring their Hippocratic Oath. How frustrating must it be for a GP to try to treat a dying patient when they do not know why they are dying?

In response to the letter of 20th August from Andipharma Mercury, we note they are unable to confirm that this shortage issue will not arise again. Whilst that may be unavoidable for technical or supply reasons, it does highlight the inherent danger of having only one licensed supplier of a crucial drug. Andipharma also don't explain why they didn't inform the MHRA of the shortage when they first realised supply would be a problem. The MHRA cannot reasonably claim lack of knowledge because, in April, they were notified by many worried patients as well as by Thyroid UK.

With regard to the Royal College of Physicians' letter of 11th September, it is difficult to comment on nothing at all. Suffice to say that, since 2011, a wealth of new evidence questions the veracity of the RCP's stance. Perhaps they are unaware that Scotland has a separate National Health Service and a devolved Parliament with responsibility for Health, and that erroneous perception has shaped their response?
