PE1463/TT

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The Scottish Government
Riaghaltas na h-Alba

In 2014 Scotland Welcomes the World

Mr Andrew Howlett
Assistant Clerk
Public Petitions Committee
T3.40
Scottish Parliament
Edinburgh
EH99 1SP

15 April 2014

Dear Andrew

SCOTTISH PARLIAMENT PUBLIC PETITION PE1463 ON EFFECTIVE THYROID AND ADRENAL TESTING, DIAGNOSIS AND TREATMENT

Thank you for your letter of 14 March 2014 seeking further information on the scope and timescale of the work to be commissioned by the Scottish Government on patients' experiences of diagnosis and/or treatment in areas where evidence is limited, uncertain or disputed.

The goal of the project is to explore how patients understand and feel about their quest for a diagnosis and/or treatment in areas where there is limited evidence, the science is uncertain or disputed and/or where a condition is rare or obscure, or not widely recognised. It is clear that for a number of people, the NHS is not providing the care and treatment they seek. There is a need to better understand the reasons for this and collaboratively find ways to improve the patient experience. Those effected by these issues go beyond those experiencing difficulties with the diagnosis and treatment of thyroid and adrenal disorders. Given that the project was prompted by the petition, a meeting has been sought with Ms Cleaver to discuss how her experiences can help to shape this work. It is envisaged that the project will take 12 months to complete but this will depend in part upon the findings of the literature review.

Elaine Smith MSP raised issues in relation to the sole supplier of T3 medication at the Committee's meeting on 18 February 2014. Decisions over whether or not to manufacture particular medicines are for Pharmaceutical Companies. As has been highlighted at the Public Petitions Committee meeting on 25 June 2013, the patient cohort receiving Liothyronine (T3) is small and it may be that companies do not see it in their

economic interests to enter into such a small market. That is a decision for the particular companies. In terms of the possibility of potency levels of T3 currently varying between batches, the Medicines and Healthcare products Regulatory Agency (MHRA) have responsibility across the UK for the licensing, supply and safety of medicines. In order to allow them to follow up on whether or not there is a difference in potency levels between current batches of T3 then it would be helpful if details could be supplied of the batch numbers, expiry date, marketing authorisation holder and product licence for the medicine. The Scottish Government would be happy to follow this up with MHRA if these details can be supplied.

I hope this is helpful.

Yours sincerely

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