

Andrew Howlett

Assistant Clerk

Public Petitions Committee

T3.40

Scottish Parliament

Edinburgh

EH99 1SP

SCOTTISH PARLIAMENT PUBLIC PETITION PE1463 ON EFFECTIVE THYROID AND

ADRENAL TESTING, DIAGNOSIS AND TREATMENT – Petitioners response to Scottish Government letter of 15<sup>th</sup> May 2013

Dear Andrew

We thank you for forwarding the response from the Scottish Government. Whilst we would appreciate a further assessment of the clinical evidence, it would only be useful if **all** the available evidence was examined, old and new. We referenced new evidence in our letter of 8<sup>th</sup> April and our original petition and would be delighted if the British Thyroid Association looked at this in depth.

Regarding the request for an Evidence note from the Scottish Health Technologies Group, we see the same problem we referenced above in in our letter of 8<sup>th</sup> April. The **published** clinical evidence can never show the true picture if research trials are not compelled to be published. Healthcare Improvement Scotland has published nothing to date on hypothyroidism and it is a glaring omission that needs to be addressed.

Finally, the Scottish Government request a further delay of between four to six months to gather the above information. We are astonished at this suggestion. Not only are lives being lost due to the current inadequate tests and treatment for this disease but patients are also facing a serious drug shortage with Liothyronine (T3). Andipharm (former name Mercury) are the **sole** manufacturer and supplier of T3 to the NHS in the UK and production ceased in April. Patients who cannot convert T4 to T3 are at risk of coma or heart attack without this medication and yet Andipharm give out conflicting information on the availability dates. We have been told they will be available by the end

of June, others told the end of September. This is a shocking, unacceptable situation and is not dissimilar to telling a diabetic patient there is no insulin. A light ought to be shone on the cost of this drug too while the Scottish Government are asking for evidence. A months supply can be bought for £1 in European countries and yet the NHS is charged £54. Patients have been told it's too expensive but the NHS is clearly not getting value for money in their purchase of this generic drug.

We respectfully urge the Petitions Committee to make an urgent decision on the setting up of a Short Life Working Group.

Yours Sincerely

Sandra Whyte

Marian Dyer

Lorraine Cleaver