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The Scottish Government

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8th March 2012

Dear Andrew

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

Thank you for your letter of 14th February 2013 seeking to establish the Scottish Government's stance on the issues relating to hypothyroidism identified in the above petition and the potential benefit in establishing a working group to examine the matter further.

The petitioners have articulated their own experiences of treatment for hypothyroidism in the petition and during the discussion with the committee on 5th February. Clearly not all these experiences have been positive which is regrettable but in the context of the NHS Scotland Quality Strategy the Scottish Government seeks to ensure that services deliver safe, effective and person centred care. Through person centred working, *improvements in diagnosis based on a whole-picture approach that takes into consideration all the patients symptoms and does not rely totally on tests* can be achieved.

In regard to the Government stance on the specific issues raised in the petition I will address these individually:

1. We ask for the inclusion of tests for Free T3 (FT3) and Reverse T3 (RT3) thyroid hormones, as these are the strongest indicators of cellular thyroid levels.

It is our understanding that the balance of T4 and T3 at tissue level is controlled by the activity of deiodinase enzymes, and as there is no medical way of influencing the activity of deiodinase enzymes there is no discernible benefit in measuring the blood levels of hormones e.g. rT3 that cannot be altered by medication.

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It is our understanding from clinical advisors in endocrinology that there would currently appear to be insufficient clinical evidence to support a general broadening of the diagnostic test for hypothyroidism. There is no evidence of any test being better than TSH and serum T4 as the main measure (but not exclusive) of thyroid function. The British and European Thyroid Associations (BTA/ETA) recommend that TSH is the best measure of thyroid function, Decisions on treatment is a matter for individual clinical assessment, most likely by an Endocrinologist in secondary care.

2. *We ask for medical professionals to acknowledge that adrenal insufficiency DOES exist and to incorporate the Adrenal Stress Index Test within NHS thyroid testing procedure.*

To the best of our knowledge Adrenal insufficiency is acknowledged by medical professionals but due to the rarity of the condition and the complexity of diagnostic testing for this condition it is not routinely part of the standard testing.

Adrenal insufficiency is more common in thyroid disease than in the general population, however it is still rare. In 10,000 people, around 1 will have adrenal insufficiency and 500 will be on thyroxine. We would expect endocrinologists to consider adrenal insufficiency in patients with on-going symptoms where they are taking thyroxine. This should be standard procedure but only if the patient appears to have appropriate symptoms.

The testing for adrenal insufficiency is not straightforward and cannot be undertaken by a simple blood test, and usually requires to be done in hospital.

3. *We ask for medical professionals to take account of variances in individual bio-chemistry and tailor treatment accordingly. Treatment may consist of: T4 only; T4/T3; T3 only or natural desiccated thyroid – or whatever combination to suit the individual patient. They must also provide appropriate support for adrenal insufficiency.*

Our understanding of the clinical evidence is that various randomised control trials have been done comparing the use of T4 versus T3 and T4 combined. Overall the trials show no benefit to the combined treatment. National expert groups such as the British Thyroid Association have only recommended the use of T4. Despite this some endocrinologists see if patients respond to a combination of T4/T3 and this is an individual clinical decision based on an individual's case and in consultation with the individual. Desiccated thyroid extract has no licence for use, and there is no robust clinical evidence for its benefit. Use of unlicensed medications cannot be recommended although clinicians do have the freedom to prescribe unlicensed medicines as appropriate for their patient. The decision whether to prescribe a specific drug for a patient's condition is based on individual patient need and is a matter for the clinical judgement of the patients doctor. Patients should, however, be fully informed that an unlicensed medicine is being prescribed and in such cases, the prescriber bears a greater responsibility.

4. *We ask for NHS procedures to include testing of autoimmune status, minerals, enzyme, and vitamins. The 'active B12' (methylcobalamin) is more effective than the current injection of hydroxocobalamin. Most Scots are vitamin D deficient, and must have high level replacement.*

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In the same way as adrenal inefficiency, vitamin B12 will be checked when clinically appropriate in the very small group of patients with autoimmune polyglandular syndrome.

Vitamin D insufficiency is an independent issue to the specific issues raised in the Petition . Although many hypothyroid patients will co -incidentally have vitamin D insufficiency, the two are not directly connected so we would require further clarification of the reasoning behind this request prior to making further informed comment.

The committee members may wish to note that it is our view that the quotes and information presented by the petitioners do not represent the full scope of views based on the overall scientific evidence.

As noted above T4 tablets are the recommended treatment of choice by the British and European Thyroid Associations (BTA/ETA) if the thyroid gland is under active. These organisations examined all the published evidence to reach these conclusions, and indicate that these are the best treatment that we have currently.

In addition in regard to the policy document from the Royal College of Physicians mentioned in the petition the committee may wish to note that this document has been written by The Royal College of Physicians, in particular its Patient and Carer Network, and the Joint Specialty Committee for Endocrinology & Diabetes; The Association for Clinical Biochemistry; The Society for Endocrinology; The British Thyroid Association; The British Thyroid Foundation Patient Support Group and The British Society of Paediatric Endocrinology and Diabetes. It is also endorsed by the Royal College of General Practitioners. During the writing of this document examination of the evidence available was undertaken and at least two patient representative bodies were included in the creation of the document.

We are aware that the committee has approached other organisations such as the RCP and Thyroid UK who are expected to highlight further clinical evidence which requires consideration in addressing the issues raised in the petition. It is therefore our recommendation that consideration be given to exploring an appropriate manner in which to establish a full examination of all published clinical evidence.

Yours sincerely

Rachael Dunk
Unit Head – Clinical Priorities