

From: The British Thyroid Foundation

To: The Scottish Parliament

Date: 14 November 2013

Re: petition PE 01463 - Calling on the Scottish Parliament to urge the Scottish Government to take action to ensure GPs and endocrinologists are able to accurately diagnose thyroid and adrenal disorders and provide the most appropriate treatment.

SUMMARY: The British Thyroid Foundation (BTF) was established 21 years ago and represents thyroid patients and their families throughout the UK, including Scotland. The BTF works closely with health professionals and aims to represent the interests of patients and improve understanding and treatment outcomes through collaboration, based on evidence that is peer-reviewed in mainstream scientific and medical journals. The BTF is aware that some patients are dissatisfied with their treatment and has drafted a hypothyroidism care strategy which is described here. The BTF has also responded below to the petitioners' specific points.

The British Thyroid Foundation (BTF) represents the interests of thyroid patients and their families throughout the UK. We have 4,346 members, of whom nearly ten per cent are in Scotland. We also have a network of 11 local patient groups around the UK (a further two are in the process of being set up) which hold regular meetings and provide a forum for dialogue between patients and health professionals leading to a greater understanding and awareness of thyroid disease from the various perspectives. Our Edinburgh group has been running for ten years and meets regularly. At the last meeting in October 2013 there were people there from as far away as Aberdeen and Inverness.

Since its establishment in 1991 we have worked closely with health professionals. We aim to improve understanding and treatment outcomes by collaboration rather than confrontation, based on evidence that is peer-reviewed in mainstream well-respected scientific and medical journals. In particular we work with thyroid specialists from the British Thyroid Association (BTA) and the British Association of Endocrine and Thyroid Surgeons (BAETS). We are one of the signatories to the Royal College of Physicians' statement 'The diagnosis and management of primary hypothyroidism' (2011) [1] alongside the British Thyroid Association, Society for Endocrinology, and others.

We provide information to patients and the public via our patient literature, newsletter and website www.btf-thyroid.org, based on available evidence. The content is produced in consultation with our medical advisors in the BTA and BAETS. We receive 3,500 phone calls and 2,000 letters and emails per year which are all dealt with, and send out patient information to enquirers (approx. 5,000) and hospitals. In the past year we have had 138,721 visits to our website (over 12,000 in the last calendar month).

It is understood that the majority of thyroid patients, including those with hypothyroidism, have their condition under control and do not seek change to their treatment or care. Nevertheless, we are aware that some patients with hypothyroidism are dissatisfied with their treatment. We note that such patients are self-selecting, and may be more likely to contact thyroid patient organisations for information, advice and support than those who feel well on their treatment regime.

The issues raised by hypothyroid patients frequently focus on concerns about:

- treatment that does not achieve an adequate quality of life
- communication problems with doctors, usually GPs, and
- perceived inaccurate diagnosis

Over the years the BTF has developed campaigns to address patient concerns with the aim of helping to improve communication, management and treatment of different thyroid disorders. We have for example made considerable progress in improving understanding and access to treatment for thyroid eye disease. Recently we have started to develop a hypothyroidism care strategy. Although at an early stage, we have drafted a plan of action for further discussion with both patients and our medical advisors.

The hypothyroidism care strategy will aim to:

- undertake a literature review of studies specifically addressing patients treated for hypothyroidism but with persistent symptoms;
- collect and analyse information from patients diagnosed with hypothyroidism, using BTF's existing databases and through specially designed surveys, to identify the most significant issues for patients about their treatment, health and well-being.
- establish more effective links with GPs, to ensure that they have access to up-to-date BTF literature for patients, and are fully conversant with the latest research and guidelines for the management of patients with hypothyroidism;
- raise awareness among medical practitioners, practice nurses, pharmacists and other health professionals of the issue that symptoms may persist in a subset of patients with hypothyroidism despite optimal replacement treatment; and
- work with patients, GPs, endocrinologists, pharmaceutical companies and pharmacy professionals to investigate how issues in the production, quality and prescribing of different brands of levothyroxine, including unplanned brand-switching resulting from generic prescribing, may affect patients and their quality of life (see MHRA report, Jan 2013 [2], reported in *BTF News 83*, page13).

The intended outcomes

The ideal outcomes for **patients with hypothyroidism** should be:

- availability of better information in GP surgeries and consulting rooms;

- a better understanding of their disorder;
- fewer repeat visits to GPs seeking alleviation of persistent symptoms;
- a better relationship with their doctor involving more satisfactory medical consultations leading to better recognition and effective treatment of persistent symptoms;
- more consistency in treatment with reliable formulations of levothyroxine;

The outcomes **for GPs, medical and healthcare professionals** should be:

- better informed patients through access to targeted BTF information and support;
- fewer repeat visits by hypothyroid patients with persistent symptoms;
- greater confidence in the consistency of levothyroxine prescribed and better understanding of issues of brand versus generic prescribing; and
- more effective treatment of hypothyroid patients with better long term outcomes and fewer complications.

The BTF response in relation to the petitioners' specific points

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.

The BTF informs enquirers that these tests are not useful in the diagnosis of hypothyroidism. Our medical advisors inform us there is no reliable scientific evidence to the contrary.

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 procedures.

Adrenal insufficiency/Addison's Disease does exist but it is extremely rare. We inform patients that adrenal testing is not justified as a routine test for thyroid disorders, although patients with ongoing symptoms should be encouraged to discuss these with their doctor.

We think it is more likely though that the petitioners are describing "adrenal fatigue", which is referred to in the evidence from Eric Pritchard (14 February 2013), Dr Henry Linder (7 March 2013), and the Thyroid Patient Advocacy group (10 March 2013), This is a term coined by Dr James L. Wilson in 1998, author of *Adrenal Fatigue: the 21st Century Stress Syndrome*[3] We have seen no evidence that "adrenal fatigue" actually exists. It is not described in the peer reviewed scientific literature, nor is it recognised by professional endocrinology organisations around the world. It is a popular definition adopted by alternative health providers. The "Adrenal Stress Index" that the petitioners refer to is a home salivary test that purports to evaluate adrenal

function and fluctuations in the circadian rhythm. This can be purchased on the internet for around £75[4].

We have also seen no evidence for the efficacy of saliva testing. There have been several studies raising questions about such tests for thyroid hormones because they can produce misleading information regarding a patient's true thyroid status[5-8] An article on this subject was published in *BTF News* 67 page 6[9].

For these reasons we inform our members and enquirers that they do not need to consult alternative practitioners, however tempting this can be if conventional medicine does not appear to have all the solutions, nor to spend money on expensive and unvalidated saliva and urine tests.

3. We ask for medical professionals to take account of variances in individual biochemistry 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.

We know there are some patients who do not feel completely well on levothyroxine medication and we sympathise with this. However, there are issues with the solutions that the petitioners propose, and it is out of concern for safety and well-being of patients with hypothyroidism that we urge caution.

The latest European Thyroid Association guidelines (2012)[10] define exceptional and experimental approaches for treating patients with a combination of T3 and T4 for persistent complaints despite thyroid hormone values within the reference range. Such patients must be carefully monitored by a specialist endocrinologist and potential detrimental effects on the skeleton and heart need to be considered carefully.

We discourage patients from using natural desiccated thyroid products such as Armour. These products are not licensed in the UK. As explained by Professor Williams at the Public Petitions Committee meeting at the Scottish Parliament on 1 October 2013, these products contain T3 and T4 in a different ratio to that normally found in humans, leading to difficulties in monitoring treatment.

We are concerned that some patients take the solution into their own hands either by consulting alternative practitioners or by ordering medicines on line from websites offering T4 and T3 products as slimming aids – for example, from <http://mymexicandrugstore.com>, as referred to in the letter from the petitioner (18 June 2013).

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.

We acknowledge that symptoms of tiredness, constipation, mild depression and weight gain, among other symptoms, can occur in untreated and under-treated hypothyroidism. However, it is important to be aware that there are many causes of these non-specific symptoms other than hypothyroidism, as reported in the article 'Challenges of Hypothyroidism' in *BTF News 78* pages 8-9[11].

We advise patients to discuss persistent symptoms with their doctor in order to establish the underlying cause and to obtain appropriate treatment.

References

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3. For an overview of how the term "adrenal fatigue" originated see <http://www.adrenalfatigue.org/> and <http://www.adrenalfatigue.org/who-is-dr-wilson>
4. The Adrenal Stress Test is available from a number of private suppliers in the UK, see for example Smart Nutrition <http://www.smartnutrition.co.uk/health-tests/adrenal-stress-test/> and Genova Diagnostics <https://www.gdx.net/uk/kitordering>
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