The Scottish Parliament
Pàrlamaid na h-Alba

PUBLIC PETITION NO.	PE01463

Name of petitioner

Sandra Whyte, Marian Dyer and Lorraine Cleaver

Petition title

Effective thyroid and adrenal testing, diagnosis and treatment

Petition summary

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.

Action taken to resolve issues of concern before submitting the petition

Elaine Smith MSP 17/11/2010 Patient Rights (Scotland) Bill: Stage 1. During this debate Elaine quotes:

'Dr Anthony Toft, a world-renowned and highly respected Scottish endocrinologist, believes that it is of prime importance that GPs consider how patients present, rather than simply accepting the results of blood tests. He suggests that doctors should take a whole-picture approach that takes into consideration all the patient's symptoms and does not rely totally on tests. That is important in the case of a lack of T3. In such a circumstance, the tests show that the T4 is fine, and the GP will insist that there is nothing wrong with the patient's thyroid function when, in fact, they are gravely ill and is getting progressively worse'.

Because Dr Toft's opinion supported our argument, it prompted us to contact Elaine Smith MSP to arrange a meeting which took place 27/03/2012. Elaine Smith MSP mentioned that she will focus on the thyroid disorders within the Patients' Rights Bill.

Scottish Parliament Meeting 27/03/2012 Sandra Whyte met with Elaine Smith MSP. Representatives from Thyroid Patient Advocacy, invited by the petitioners, were in attendance. Margaret McGregor (Thyroid UK) and Brian Cooney were also present. Sandra suggested that this lack of acknowledgement, testing and treatment regarding the T4-T3 conversion problem by medical professionals is against our Human Rights. Elaine asked Brian Cooney to investigate. Elaine made it clear she wanted to take this debate further and suggested we have a further meeting. She also suggested we submit a petition. Sandra agreed to do this as she and Marian had already instigated action on this subject in Scotland.

To highlight that this is not just a Scottish problem, we contacted 'Thyroid Change' a World Movement to effect positive change in the outdated, ineffective and, frequently, dangerous adherence to the T4-only policy. It has members from 125 different countries and they fully support and endorse this petition.

2/8/12 Meeting with James Dornan MSP's assistant. Lorraine Cleaver met with

Stewart McDonald to discuss the problems thyroid patients have obtaining appropriate medication and was advised to submit a petition to the Scottish Parliament.

Petition background information

This Petition from Sandra Whyte, Marian Dyer and Lorraine Cleaver (Scottish residents) is informed by our personal traumatic experiences of thyroid/adrenal debilitating disease. Many erroneous diagnoses were explored spanning decades which left us homeless, jobless, penniless and close to death.

The current T4-only treatment, prescribed by the General Medical Council (GMC), is inadequate for patients who do not convert T4 to the active T3. This must be rectified urgently

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.

Free T4 must convert to FT3 for the body to have energy (active metabolism). RT3 causes energy depletion by blocking the active FT3 from getting into the cells.

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.

The adrenals, which sit atop the kidney, are important for cortisol production and become exhausted trying to compensate the fatigued body for the lack of thyroid hormones. They release cortisol as a means to deal with stress in the body until they, too, become underactive ... if your adrenals are low, the thyroid hormone cannot 'get into the cells'. Your cortisol has to be at a certain "level" to allow the thyroid hormone to do its job. If not, it will adversely affect the T4-T3 conversion. Severe ill health follows and, yet again, the endocrinologists refuse to recognise adrenal insufficiency.

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.

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.

Supporting Studies

In 1997, endocrinologists attempted to correlate the classic symptoms and physical findings associated with hypothyroidism with modern thyroid blood tests. This was the first study in almost 30 years in which doctors made any effort to demonstrate the clinical efficacy of thyroid function tests. The results were published in the Journal of Clinical Endocrinology.

"It is of special interest that some patients with severe biochemical hypothyroidism had only mild clinical signs, whereas other patients with minor biochemical changes had quite severe clinical manifestations. Thus, we assume that tissue hypothyroidism at the peripheral target organs must be different in an individual patient. Therefore, the clinical score can give a valuable estimate of the individual severity of metabolic hypothyroidism. JCEM. 1997; 82(3)771-776

A May 2000 paper: **Thyroid Function Tests – Time for a reassessment BMJ 2000 May 13; 320 (7245): 1332-1334** concluded 'as it becomes clear that biochemical assessments cannot deliver the diagnostic accuracy expected of them, the fact that the clinical aspects of assessing thyroid dysfunction are being sidelined is a cause for concern.' Doctors are supposed to use this TSH test as just one indication and a tool

towards diagnosis and yet they are using it as a sole indicator. If the TSH falls within their accepted, though hotly disputed, range, the patient is generally told the thyroid is fine and sent away to suffer.

A paper published in the BMJ 2003. Serum thyroid stimulating hormone in assessment of severity of tissue hypothyroidism in patients with overt primary thyroid failure: cross sectional survey.

Comment: *TSH is a poor measure for estimating the clinical and metabolic severity of primary overt thyroid failure. This is in sharp contrast to the high diagnostic accuracy of TSH measurement for early diagnosis of hypothyroidism.*

We found no correlations between the different parameters of target tissues and serum TSH. Our findings are in accordance with a cross sectional study showing only a modest correlation between TSH and the percentage of positive hypothyroid symptoms and data showing discordant responses between the pituitary and peripheral target tissues in patients treated with L-triiodothyronine. We assume that secretion of TSH is driven by maximal stimulation, with no further increase occurring with greater severity of hypothyroidism. Therefore, the biological effects of thyroid hormones at the peripheral tissues—and not TSH concentrations—reflect the clinical severity of hypothyroidism. A judicious initiation of thyroxine treatment should be guided by clinical and metabolic presentation and thyroid hormone concentrations (free thyroxine) and not by serum TSH concentrations. (BMJ. 2003;326.7384.311)

Swedish Study says 70% patients are not symptom free on T4 only. March 2011

http://www.sourze.se/Forskare_ser_omvandlingsproblem_med_Levaxin_10742982.asp

The Royal College of Physicians (RCP) and the British Thyroid Association (BTA) offer different definitions of hypothyroidism.

The BTA states “The clinical consequences of insufficient levels of thyroid ***in the body***”.

The RCP states “The clinical consequences of insufficient secretion ***by the thyroid gland***”.

The RCP also state “Patients with continuing symptoms after appropriate thyroxine treatment should be further investigated to diagnose and treat the cause”.

The above statements show an acknowledgment that there can be more than a **thyroid gland** secretion problem. Patients who are treated with thyroxine and who have **continuing symptoms** may have a T4 to T3 conversion problem and should have the appropriate tests to see if all the right hormones are being transported to the **cells in the body** to provide energy. As thyroxine is not the appropriate medication for non-converters, a full metabolic screening test should be carried out before thyroxine is administered.

As for the decades-long diagnostic debate, a 2000 Scottish study, titled **Thyroid function tests – time for a re-assessment** concluded: ‘A remarkable downgrading of the clinical aspects of hypothyroidism and hyperthyroidism has paralleled the inexorable increase in the number of thyroid function tests performed over the past 20 years. This has led to chaos in the diagnosis of hypothyroidism.’ BMJ 2000 May 13: 320 (7245): 1332-1334

As recently as November 2012, another clinical study, **Is Pituitary Thyrotropin an Adequate Measure of Thyroid Hormone-Controlled Homeostasis During Thyroxine Treatment?** Concluded … T4 treatment displays a compensatory adaptation, but does not completely re-enact normal euthyroid physiology. This invites a study of the clinical consequences of this disparity.’ PMID 23184912

Scotland’s heart disease problem is also implicated in bad thyroid diagnostics. This study, **Subclinical Hypothyroidism and the risk of coronary heart disease and mortality** concluded that ‘subclinical hypothyroidism is associated with an increased risk of coronary heart disease events and mortality in those with a higher TSH levels’. PMID 20858880 [PUBMED - indexed for medline]

Metabolic screening tests are already available internationally. As we have ‘state of the art’ medical research and development facilities in Ninewells Hospital, Dundee, these tests could be done here in Scotland. Also in Dundee, Axis Shield’s Active B12 test has the potential to make Scotland a world-leader in the diagnoses and resolution of these metabolic imbalances. Not only would we have a much healthier population but we could save a fortune by dispensing with outdated, inadequate and, usually, inappropriate testing.

Unique web address

http://www.scottish.parliament.uk/GettingInvolved/Petitions/PE01463

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NO

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3

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