PE1463/H

THYROID PATIENT ADVOCACY (TPA)

To the Honourable Members of the Scottish Parliament: 10 March 2013

PE01463 – Effective Thyroid and Adrenal Testing, Diagnosis and Treatment

INTRODUCTION: TPA is a registered charity with over 5500 members who are seeking support because they are not being returned to optimal health by their doctors using the present diagnostic and treatment protocol for their thyroid and adrenal conditions. Our aims are to ensure that all sufferers of symptoms of thyroid and thyroid related disease will be comprehensively examined, biologically tested, diagnosed and treated appropriately - with medication suited to their specific needs.

Both Endocrinology and patients are being failed by the Royal College of Physicians (RCP) owing to their refusal to accept simple facts that have been known for half a century. The RCP fail to recognise around 15% of patients suffer chronically on the conventional treatment using the pro-hormone levothyroxine (T4) monotherapy. These patients need a different diagnosis and therapy protocol.[1-3] The RCP policy statement on the Diagnosis and Management of Primary Hypothyroidism goes beyond 'Primary'[4] and it is this that is causing confusion for doctors and patients alike.

OBJECTIVE: To correct errors in diagnosis and treatment which fail to recognise the complete thyroid system (see The 'Greater Thyroid System Table). This includes peripheral metabolism, reception and mitochondrial energy production, which are being ignored.[5,6] TPA emphasise the role of the active thyroid hormone triiodothyronine (T3) as the essential effective treatment for many patients with symptoms of hypothyroidism.[7-93].

BACKGROUND: How has confusion on this topic come about?

- Ignoring studies on the characteristics of peripheral metabolism,[7-93] ignoring warnings of the failure of T4 monotherapy,[3,187-189] ignoring studies showing treatment with T4-only to be ineffective,[94-112] and ignoring the fact that of those treated with T4-only, many remain ill.[122]

- Ignoring the greater activity of T3 over T4.[190] A hormone with greater activity can not be ineffective unless the studies are a special case.

- Ignoring the potential for euthyroid hypometabolism (EH) showing that a person can have the symptoms of hypothyroidism with normal thyroid function and that intracellular chemistry depends upon T3, not T4.[2,3]

- Ignoring the physiology that connects the thyroid gland to the peripheral, symptom-producing cells.[189,191]

- Ignoring Differential Diagnostic Protocol, which requires testing of all potential physical causes.[113-116]

- Ignoring patient counterexamples to T4-only therapy whose symptoms were mitigated, or remitted, after treatment with T3.[117]

- Ignoring the imprecise language that has contributed to false conclusions and unacceptable standards of care.[118,175-181]

- Ignoring the evidence suppression condoned and encouraged by evidence-based medicine.[136.137]

- Ignoring the fallacy of applying average solutions to every patient, including those with chronic symptoms of hypothyroidism.

- Ignoring the errors perpetrated by various anti-T3 studies and meta-analysis, circa 2000-2006.[182-184,186]

- Ignoring, by the RCP and GMC, physiology other than that of the thyroid gland, which includes failure of peripheral utilisation. The GMC Endocrine curriculum does not include teaching and testing of trainee's competence in recognising the full array of manifestations of thyroid system failure (skills and behaviour of intracellular chemistry). Therefore, trainees do not understand the physiology and biochemistry of thyroid hormones, and are therefore not competent to diagnose, manage and provide care for all patients with thyroid related disease until this has been rectified.[123,192]

- Ignoring the common syndrome of thyroid and adrenal fatigue and the science showing the above syndrome has global effects, together with imbalance of other hormones, the likely presence of systemic candidiasis and dysbiosis, malabsorption, low levels of nutrients and food allergy.[94-112] Scottish citizens have the lowest life expectancy in the Western world, and have extreme vitamin D deficiency. Scotland receives 30-50% less ultraviolet radiation (UVB) from the sun than the rest of the UK.[172-174] Low levels of vitamin D results in poor absorption of thyroid hormone.

- Ignoring all rebuttals submitted to RCP policy statement. TPA submitted a rebuttal 2010.[134] The President's response was "*the College cannot enter into any further correspondence on this issue*". TPA submitted a further rebuttal in July and September 2012, and again in January 2013.[135] In February 2013, the RCP confirmed that *"The RCP position has not changed".*

Imprecise Language attached to thyroid disorder: The British Thyroid Association (BTA) and the RCP position statements[1,119] do not stipulate definitions and do not provide logical consistency. Both these statements are about the thyroid gland, not other physiology which should be treated with T3, and not T4. The Scottish Parliament must urge for such clarification on the interpretation of 'hypothyroidism' and the maintenance of logical consistency in new thyroid guidelines.[120] Only then would doctors be either free to treat continuing symptoms of hypothyroidism, or would be properly guided.[118]

Possible Diagnostic Solutions: The RCP position statement recommends that patients with continuing symptoms who are prescribed T4-only should be further investigated to diagnose and treat the cause of their symptoms, yet it fails to specify what should be tested (see The 'Greater' Thyroid Function

Table'). New thyroid guidelines must make this clear. The genetics of how people are critically different in respect of T4 to T3 conversion was published in 2003.[121] The position statement fails to take account of this. If medical science and patient counterexample experiences were recognised, patients would be given the correct treatment.[122]

- Dr. P. Abernethy, states in *"SIGN 50: A Guideline Developer's Handbook*" (a) *…the case of Hunter v. Hanley establishes the customary standard of care for evaluating medical negligence*,[171] and (b) *… the case of Bolitho v. City and Hackney H.A. found that if the customary standard of care is not logical, the judge is entitled to determine that the defendant's expert's opinion was not reasonable or responsible*.[172]

The evidence gathered by TPA indicates that Endocrinology's stance and continuance of T4-only therapy for all suffering hypothyroid symptoms, is without basis and harmful to thousands of sufferers.[117]

Correction of Misleading Thyroid Function Tests: Thyroid Stimulating Hormone **(**TSH) is a hormone secreted by the pituitary gland that stimulates the thyroid gland to produce T4 and T3. T3 stimulates the metabolism of almost every tissue in the body. An abnormal TSH indicates an excess or deficiency of thyroid hormone at the periphery, but it does not indicate the reason why. US Endocrinology has recommended narrowing the TSH reference interval to 0.3 to 3.0 contrasting with the RCP policy statement recommendation of 0.5 to 10.0. Sweden, Belgium and Germany have an upper value of TSH of 2.5. The Scottish Parliament should urge that the TSH range should conform to the latter, and that this information should be printed on TSH laboratory reports for clinician guidance. The links between those suffering hypothyroid symptoms and Infertility, diabetes, elevated cholesterol and increased cardiovascular events[125-132] are well documented and represent the hazard of misdiagnosis when the TSH reference range is too large.

Ending the "T4-only" protocol of treating ALL patients with symptoms of hypothyroidism: Prescribing T4-only is commonplace for those suffering with primary hypothyroidism according to the position statement. However, T4 cannot work for those suffering failure of peripheral utilisation. Studies that confirm between 9 and 15% of those treated with T4-only are unable to convert T4 to T3 are being ignored [7-14] and doctors have reported patient dissatisfaction with T4-only therapy.[15-18] These patients need a combination of T4 and T3, or natural desiccated thyroid extract (NDT) should be considered. (NDT was the only treatment for all, prior to the introduction of T4-only therapy). Many patients using NDT are reporting a resolution of all the problems encountered whilst on T4 only which may be due to the fact that NDT contains all the hormones a normal thyroid produces. Continuing belief that T3 therapy is of no clinical value has led doctors to make decisions that adversely affect their patients' health, whereas scientific facts and research have established its efficacy. We ask the Scottish Government to urge medical practitioners to make a full assessment of the clinical presentation of patients already on NDT therapy.

Doctors Autonomy – and Fear of the GMC: Reliance by the GMC upon the RCP Policy statement is resulting in inappropriate disciplining of doctors who treat patients with anything other than T4, and doctors who are prepared to introduce thyroid hormone therapy in the situation of patients with symptoms of hypothyroidism who show ”normal” thyroid blood tests. The MHRA affirms that: “….*Clinicians should have the ability in appropriate circumstances to exercise their professional judgement to commission the supply of an unlicensed medicine to meet the special needs of an individual patient”.*[133] The DoH has confirmed this assertion. The GMC interferes with, and penalises doctors, when they are correctly, effectively, economically and safely treating their patients on the basis of robust science.

Drug sales are underpinning the current approach to thyroid disease, instead of consideration being given to the health and well being of the population. Untreated or under-treated patients suffering hypothyroid symptoms chronically use more prescription drugs, e.g. diabetes, cardiovascular disease, elevated cholesterol, gastrointestinal conditions, depression, anxiety, memory loss and Alzheimer’s, all of which can be associated with lower thyroid levels.[148] Research has shown improvement can be achieved with the correct thyroid hormone replacement.[138-170] and this has important implications for controlling the cost of healthcare.

The Scottish Parliament should urge the Scottish Government to check the evidence suppression of evidence-based medicine.[136,137] Such suppression is contrary to Scottish custom and case law. TPA also urge the issue of new guidelines that will acknowledge and encompass the scientific facts and research mentioned above and rely less on faulted “evidence” EBM and more on “results” based medicine, and that new guidelines are written by those who have no connection with the pharmaceutical industry, directly or indirectly. TPA earnestly seeks the support of the Scottish Government in remedying this appalling situation in Scotland and thereby improving the quality of life of tens of thousands of patients in the UK alone, and potentially, millions world-wide. A timely and radical review would be welcomed by an increasingly knowledgeable and empowered public, as well as by those doctors currently struggling to provide what they know to be the most appropriate treatment for their patients.

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LINK TO REFERENCES: http://tpauk.com/forum/content.php?1051-References-for-Thyroid-Petition