PE01463 Effective Thyroid and Adrenal Testing 8th April 2013

PETITIONERS: Sandra Whyte, Marian Dyer and Lorraine Cleaver response:

To David Stewart MSP and the Petitions Committee

We thank you for all your assistance with the above petition. We are grateful to the many doctors and organisations who submitted letters and references in support of this and, in the interest of brevity, wish to state that we are in complete agreement with the statements given therein, with the exception of the Scottish Government and, by extension, the GMC.

We note the Royal College of Physicians did not reply to your questions and, whilst not overly surprised, we are disappointed as the health of many thousands of Scottish people is suffering as a result of their policy statement.

Regarding Rachael Dunk's letter for the Scottish Government, we appreciate that you appear to recognise the need for a 'whole-picture' approach and that a number of symptoms – often seemingly disparate – are involved. However, we must emphasise that the endocrine establishment apparently chooses to ignore this 'whole picture' and, worse, seems to cavalierly disregard the uniqueness of each individual's manifestation of symptoms. We are very disappointed with this archaic view. As long ago as 1997, Julian Tudor Hart, at a Cochrane Lecture 'What evidence do we need for evidence based medicine?' said, "Hasty, thoughtless, insensitive clinical decisions which do not use all available and relevant biological knowledge are less efficient and more costly than unhurried, thoughtful, sensitive decisions which do.".

Our experience indicates that professionals prefer to base both diagnoses and treatments on specific tests and a dogmatic adherence to an erroneously established reference range. Their unwavering reliance on such tests and seemingly arbitrary laboratory reference ranges has, all too often, left people in a state of deteriorating health. At its most basic level, this is an unprofessional departure from the Hippocratic Oath. In its entirety, it surely must be a crime against humanity and against our individual human rights. On a more practical level, the associated costs to the public purse are a significant drain on already squeezed resources, not to mention escalating social and financial costs from progression to ever more serious diseases such as heart disease, cancer, diabetes and more.

Dr. Lindner's letter to the Petitions' Committee amply demonstrates that professional conclusions are not only illogical but many have been disproved by available scientific studies. "Normal" TSH and Free T4 results do NOT rule out hypothyroidism. The TSH test is NOT a valid measure to guide treatment. FT3 and RT3 levels are essential to getting the fullest view of the body's thyroid levels and effects. It is also well documented that "normal" AM serum cortisol or ACTH stimulation tests do not "rule out" adrenal insufficiency. We would very much appreciate hearing your response to the evidence Dr Lindner has provided.

The Scottish Government's letter merely states standard endocrinology assumptions and guidelines, most of which Dr Lindner has demonstrated are illogical and/or directly contradicted by the available evidence. Medical organizations will ultimately try to cover up their failings by saying "the decision is always up to the clinical judgment of the practitioner". However, that contradicts the fact that their teachings and guidelines leave practitioners unable to accurately diagnose or properly treat most hypothyroidism and most cortisol deficiency states. Moreover, they then persecute any doctor who doesn't follow these uninformed guidelines. Consequently, many patients are left ill and at serious risk of premature death.

Of particular interest to us was the comment that 'there is no discernible benefit in measuring the blood levels of hormones eg Reverse T3 (rT3) that cannot be altered by medication'. This is rather disingenuous because, if high rT3 is found, removing or reducing the T4 medication can help to clear this (patients have noted good lowering in about 8 weeks; some need more time) before different medication is trialled. In The Journal of Clinical Endocrinology & Metabolism 2005; 90(12):6403-6409, it is noted: 'this study demonstrates that TSH and T4 levels are poor measures of tissue thyroid levels, that TSH and T4 levels should not be relied upon to determine the tissue thyroid levels, and that the best estimate of the tissue thyroid effect is the rT3 level and the T3/rT3 ratio.' This would seem to indicate that rT3 has indeed great value in hormone testing.

This letter further includes the assertion that: "The testing for adrenal insufficiency is not straightforward and cannot be done by a simple blood test, and usually requires to be done in hospital." In this, Ms Dunk is correct. However, there are varying degrees of adrenal insufficiency and the earlier stages are more thoroughly diagnosed by the Adrenal Stress Index test – a 24-hour saliva collection which is done at home. It's far less expensive than the Short Synacthen Test and far more appropriate for hypothyroid patients. Although it is acknowledged on thyroid medication patient leaflets that adrenal problems should be ruled out prior to commencing thyroid treatment, this is rarely, if ever, done.

The assertion that B12 deficiency will be "checked when clinically appropriate in the very small group of patients with autoimmune polyglandular syndrome" is deeply worrying. A plethora of research proves this deficiency is extremely common in hypothyroid patients and is rarely screened for. A 2008 study by Jabbar, Yawar et al notes: Our study showed vitamin B12 deficiency to be common in this population of hypothyroid patients. Screening for B12 deficiency should be undertaken early in the diagnosis of hypothyroidism and periodically thereafter. Patients should be followed and evaluated for suggestive symptoms http://www.jpma.org.pk/full_article_text.php?article_id=1394

A further study concludes 'patients with autoimmune thyroid disease have a high prevalence of B12 deficiency and particularly of pernicious anemia'. AM J Med Sci. 2006 Sep; 332(3):119-22. We are very concerned that the endocrinology speciality seems to be either unaware of this research or unwilling to take it on board. The 'ACTIVE-B12 '(Holotranscobalamin) assay from Axis-Shield is a new and innovative way of assessing Vitamin B12 levels and offers improved accuracy, sensitivity and specificity over the current out-dated front-line tests.

Vitamin D insufficiency is not an independent issue for thyroid sufferers, as Vitamin D is needed in the conversion of T4 to T3 thyroid hormones. A March 2013 study which can be seen via this link http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0058725 concluded "Our data suggest that any improvement in Vitamin D status will significantly affect expression of genes that have a wide variety of biologic functions of more than 160 pathways linked to cancer, autoimmune disorders and cardiovascular disease which have been associated with Vitamin D deficiency.

This study reveals, for the first time, molecular finger-prints that help explain the non-skeletal health benefits of Vitamin D. You will no doubt be aware that the Scottish population in general has low levels of Vitamin D. As optimal vitamin D levels are essential for hypothyroid sufferers, we find it disturbing that this is seen as an independent issue. The majority of thyroid sufferers have to fight to get these vitamins and minerals tested despite the fact that, along with iron, folate and several other vitamins, minerals and enzymes are essential for effective utilisation of thyroid hormones. Rarely do endocrinologists even mention these to unsuspecting patients and, when informed patients bring them up, they are roundly dismissed as unnecessary so patients are forced to pay for private testing.

We would like to come back to Rachael Dunk's comment that, during the writing of her document, examination of the available evidence was undertaken. We have recently received further evidence that was not examined. Some is mentioned above and a new paper casting doubt on the lack of importance of T3, here http://www.med.miami.edu/news/miller-school-studies-show-brain-and-heart-cells-regulate-thyroid-hormone-f/.

Further, as you may be aware, there is an AllTrials initiative currently gathering pace to compel the publication of all clinical trials. As it stands, less than half of all clinical trials are published. Sir Ian Chalmers of the James Lind Initiative says this is "unethical and scientific misconduct". We agree with his statement. We are expected to take the one and only recommended hypothyroid medication, levothyroxine, on faith that it has been trialled successfully and yet the MHRA hold no records of it ever being tested for safety and efficacy. The fact that it has been in common use for decades seems to be deemed evidence enough, despite the multitude of side effects reported by patients who take it. These symptoms are then dismissed as 'not thyroid related.' We wonder why the same 'common usage' standard does not also apply to natural desiccated thyroid?

The American Thyroid Association's Spring 2013 Conference has the heading 'Treatment of Hypothyroidism: Possibilities on the Horizon' and the introduction says "The expectation that use of levothyroxine would provide complete resolution of the constellation of symptoms that characterise hypothyroidism was a reasonable but, nevertheless, overly optimistic hope." It would seem that the matter is not settled yet, despite the apparent stance of the Royal College of Physicians. A new randomised, double-blind crossover study, Desiccated Thyroid Extract (DTE) compared with levothyroxine (l-T_4) in the treatment of Hypothyroidism concluded that "The results of this short-term investigation with a relatively small number of subjects indicate that thyroid hormone therapy with once-daily DTE in place of l-T_4 causes modest weight loss and possible improvements in symptoms and mental health without appreciable adverse effects, Studies with a longer duration would clarify the efficacy and safety of DTE." http://www.ncbi.nlm.nih.gov/pubmed/23539727

The majority of sufferers from thyroid illness are women. Perhaps that has some bearing on why this situation has remained unresolved for so long? Many women languish miserably and unproductively under the 'modern labels' – eg chronic fatigue, fibromyalgia and depression – that pass for diagnoses today. It is not an exaggeration to suggest that most of these women could be helped through a policy of more sensitive, individualised endocrine diagnosis and treatment. Attached are examples of the tests that we wish to see used in this individualised diagnosis.

In summary, we believe the diagnosis and treatment of thyroid and adrenal disease is in disarray and has been for decades. Medicine has previously made wrong turns, mistakes are made and science learns from them. It is now high time that endocrinologists adjusted their whole approach to this disease and took full note of the current medical evidence. Patients will not put up with this shocking mistreatment for much longer, if at all. The petitioners may be only three anecdotes who almost died but they speak for a worldwide thyroid community and have the support of doctors who are world authorities on the speciality.

The following links are the 3 tests we are seeking the petitions committee to recognise, that will diagnose the many undiagnosed Hypothyroid and Adrenal Insufficiency patients who are still suffering due to the present inappropriate testing.

1. Thyroid Plus shows the basic TSH, T4, FreeT4, plus Peripheral Thyroid Function, Thyroid Auto Immunity, ReverseT3 can be requested, which gives a complete thyroid screening. http://www.gdx.net/uk/core-uk/sample-reports-uk/Thyroid-Plus-Sample-Report-END27.pdf

2. Adrenal Stress Index; for diagnosing the different stages of adrenal stress. The ASI also allows hypothyroid sufferers to be checked to see if they have sufficient cortisol levels for optimal thyroid function, before commencing thyroid treatment. It is more sensitive and less invasive than the present Synacthen test which is used mainly for diagnosing Addison's Disease and Cushings Syndrome.
http://www.gdx.net/uk/core-uk/sample-reports-uk/ASP-Sample-Report-END01.pdf

3. Metabolic Analysis Profile: encompasses vitamins, minerals, enzymes, Kreb's cycle, methylation, mitochondrial dysfunction, neurotransmitters and more... It could significantly reduce costs currently incurred by having these tests done separately.
http://www.gdx.net/uk/core-uk/sample-reports-uk/Metabolic-Analysis-Sample-Report-MET02.pdf

Scotland is famous throughout history for being a leader in medical advances and this is a fantastic opportunity to reverse the shameful treatment meted out to thyroid/adrenal patients. We agree with the Scottish Government's assertion that they see merit in examining these issues in depth.