

PE1463/HHH

Rebecca Turner Letter of 10 February 2016

Dear Committee,

As a thyroid patient and personal friend of the petitioner, I wanted to lodge my disappointment at the shambolic behaviour of both the Scottish Minister for Health and Prof Leese at yesterday's meeting to discuss the above petition. As someone who contributed to the TUK survey in good faith, I was disappointed to see it dismissed out of hand as 'anecdotal' and yet both the Minister and Prof Leese were able to get away with making statements such as 'theoretical issues with safety' of NDT and other such unsubstantiated nonsense themselves. I congratulate the committee on their fair handling of what was an embarrassing episode, and for pushing both witnesses to provide straight answers.

The Minister's rambling and disjointed statement on guidelines was painful to watch, I gasped when she implied that the petitioner would have come up with them herself. This was an insult to all the hard work that has gone into this petition and a gross misunderstanding of why the petition was lodged in the first place. Mrs Cleaver did not meet with Sign, indeed I believe she wrote to the committee stating that she felt the entire process would not be impartial due to the conflicts of interest of the endocrinologists involved.* Sign guidelines DO NOT exist – and I believe they were to have made up only one part of a far more comprehensive listening exercise. If the minister's idea of a listening exercise is parroting the existing woeful guidance, then we might as well all pack up and go home.

If the minister was referring to BTA guidelines, they are the reason the petition was necessary in the first place. The minister also seemed to be confused about institutions, muddling up the BTF, the BTA, and TUK. She also seemed muddled about medications, referring to NDT as 'liothyronine' thus further confusing matters. It really was most frustrating to see valuable time being wasted by someone who clearly did not have the ability to speak with any authority on this subject.

I do not blame Mrs Cleaver for walking out of the meeting, as their performance was an insult to the suffering of thousands upon thousands of thyroid patients, mainly women, who are watching this petition's progress with great interest – in both Scotland and Great Britain (as patients in the rest of the UK are hoping Scotland might blaze a trail on this issue). Given hypothyroidism's devastating effect on fertility, pregnancy and miscarriage, this truly is a women's rights issue, knocking onto reproductive and maternity rights as well as our right to have equal access to decent healthcare – women's bodies are far more hormonally complex than men, thus thyroid disease has an absolutely devastating effect on women. Women are still disempowered when knocking up against the male power structure that is medicine, thus further worsening our chances of being taken seriously. Thyroid disease also has a huge economic effect on patients, with many who had formerly successful careers being rendered unemployed due to ill health, not to mention the ridiculous sums of money wasted on other drugs and tests to determine what is 'wrong' with these heart sink patients.

The petitioner has now spent four years collating and submitting a great deal of evidence, and has also encouraged many well respected scientists and doctors to do the same. I would like to see some of these other experts able to present to the committee, as well as the petitioner herself being able to have the chance to rebutt some of the frankly ludicrous claims made yesterday.

Nobody is suggesting a 'conspiracy theory' (apart from him), what we are suggesting is a stubborn refusal to look again at a treatment pathway that is not working. Most thyroid studies are badly designed, and if you ask the BTA for a copy of the 'overwhelming evidence' that they state confirms levothyroxine is the 'gold standard' of treatment, you will be told it was 'never collated' – how is this possible?? 'Never collated' is Quack Speak for 'doesn't exist'.

The really bizarre thing about all this is the complete lack of curiosity on behalf of mainstream medicine towards this issue – they doggedly defend a hypothesis, and then when presented with evidence that seems to counter it (anecdotal or not) they seem to have a total lack of interest in puzzling out why this might be.

Myself for instance, I had a total thyroidectomy for Graves disease, hashimotos disease, hashitoxicosis, thyroid eye disease and papillary thyroid cancer in 2011 after a DECADE of misdiagnosis. Unlike the petitioner, whilst on 175mcg levothyroxine (a treatment I complied with 100% for nearly two years post surgery) my thyroid biochemistry was 'perfect' according to BTA guidelines, and yet I was beset by torrential and debilitating symptoms that rendered me almost bed bound and ended a £100k a year career. I now self medicate on NDT, and whilst my blood results are pretty much identical to what they were on levothyroxine the transformation would have to be seen to be believed (please see before and after photos attached, the last from Sept 2015 showing me after 2 years of natural hormone treatment). If science cannot explain this, then surely there is something wrong with the 'science'?

The petitioner has submitted compelling and high quality evidence that the science behind the biochemical tests is flawed, the reliance on the TSH is not valid, the reference ranges are arbitrary, the list goes on and on. As for the Professor's worry with regards to the 'theoretical safety' of natural thyroid, I would point out that the safety of levothyroxine is theoretical also, as NO SAFETY STUDIES were ever conducted, it was simply launched on unsuspecting patients who were then at the same time held hostage to blood ranges that were pretty much plucked out of the air. Patients who had formerly been quite happy on Natural Thyroid – which has over a century's successful use behind it.

As someone who has nearly lost my life to this disease, who has sat through many endocrine consultations in tears whilst the doctor never took his eyes off the computer screen (scrutinising my blood results), I implore you to keep up the good work and keep asking for answers. I should not be forced to buy drugs online, or pay for tests myself because nobody will help me.

You have now witnessed first-hand the Monty Python-esque circular arguments that women are subjected to day in and day out, it MUST STOP!! It is intolerable that our symptoms are written off, or worse denied and our lives and livelihoods ruined. I

congratulate the committee for supporting this petition so far, and Elaine Smith for her ongoing tenacity on this subject and wish her all the best.

Yours sincerely

Rebecca Turner
Thyroid Patient

*Miss Turner corrected the statement in a further e-mail to note that Mrs Cleaver did initially meet with Sign, which prompted her concerns re impartiality of any potential Sign guidelines.