

PE1463/JJJ

Jo Morris Letter of 13 February 2016

To the Scottish Parliament Committee,

I have been following this petition and the very slow progress through your system and have watched the last 'episode' on Youtube.

Thankfully some on the committee could see that the health minister and Prof. Leese were ill prepared, did not know what they were talking about, passed the buck and could not answer significant and relevant questions. Is this perhaps a lack of caring and knowledge?

I saw one of the two people 'on the defence' and was quite indignant that they should be brought before the committee and questioned at all.

I am writing to let you know I was disgusted and disappointed with what I saw and heard, and hope this does not continue and that the committee see's through this lack of commitment and orders changes?

Why these 'people' are allowed to show up with an inability to show they have researched the subject in a **non-biased** and 'compassionate' manor makes me think their participation is a complete farce and that they are only there to create road blocks and stall any progress. Something was amiss.

At the very least the people who this affects most, should also have been able to contribute at this session as they could have replied to the responses with correct data, as so much was left out. There needs to be a debate between the two parties (both sides in the room contributing) – as this system seems to be a little flawed or unfair in my opinion.

We here in New Zealand and in many other countries around the world are watching this unfold with interest, as this is an International problem that has to be addressed, it cannot go on.

In Australian Parliament at the moment they are looking into ME/CFS and lack of funding or help to sufferers or understanding of the condition (commonly suggested to be linked to undiagnosed Thyroid conditions also).

We are not all suffering from mental illness (yes you do get down when you're not being taken seriously and fobbed off with anti-depressants that you don't need – take a walk in our shoes) – that has been proven when people are given T3 or the Natural Porcine T4/T3 (also contains T2, T1 & Calcitonin) combination drug (in correct doses, **not under dosed**) and several forms of mental illness may actually be mis or undiagnosed Thyroid disease.

Perhaps we need more women on these committees to get more balance? Elaine has been through the same as all of us – we have endured years of tests and procedures to no end and no diagnosis or a 'clutching at straws' diagnosis– how taxing is that on the health system and on us the sufferers?

I have a background in Pharmacy and Natural Therapies, I know how to interpret research.

I would love to see these 'Research' papers Prof. Leese keeps referring to, as those I have researched and read myself are suitably manipulated to the drug companies or researchers 'ends', with very few participants included or correct doses given and not focussed on the areas we need, or they exclude the very people who need to be in the research.

I suggest the committee try looking for non-manipulated research themselves.... It is very hard as there has not been enough done and it is skewed toward cancer, radiation, selenium and iodine anyway. Also – remember that a lot of research is being found to be flawed and fraudulent with for example, 'pesky women's hormones' skewing results so have had their data omitted from the studies and only the men's data used. It's not easy to find good research and no-one has the time to look at it all to prove its good or bad research. (I think that is what they count on). There is a lot of money wasted funding bad research.

I would love to hear what the theoretical 'dangers' are for taking this medication that Leese kept mentioning - without tabling proof, (is it arrhythmia or heart disease or something else?)? I had palpitations due to too low a dose, increased my Whole Thyroid Extract and it's gone.. It is actually a good indicator to the dose being too low.

I'm sure one hundred and thirty (to 180?) plus years of previous acceptable use is the best research you could ever hope for, for the natural T4/T3 combination product, my own great grandmother being one of those who survived a long life on this Porcine Drug (without reliance on blood tests). This treatment was accepted and yet it has been treated as the most unacceptable treatment since a synthetic, profit driven, singular drug was created, based on a flawed understanding of Thyroid hormone production and utilisation in individuals.

We feel the problem stems from the way Dr's are taught and know the drug companies have much input into what they are taught, this is problematic. Why are we letting the Health 'professionals' and drug companies (with their biases) decide what is right from their research only, to say that we don't need to have the active form of T3 (either natural or synthetic form)? Yes 'the active form'....

Would you be happy to take an inactive form – that needs to be 'activated' by a chemical process that you may not be capable of generating (genetically) or due to iodine or other deficiency? You may not have a high TSH to show you have this problem (I didn't) – it is not that 'cut and dried' and the genetic problem is only one of many, there is a huge scope of possible problems for each individual. No one is going to test you for this they will only look at your TSH levels and give you synthetic T4, this is just one area being ignored. This synthetic T4 is also toxic to some individuals – who suffer even worse symptoms (but are told it's in their head).

It angers me that the arrogance and self-supposed superiority of these people is acceptable over and above our claims, as if we are not intelligent human beings who are knowledgeable about our own bodies.

I would like to draw your attention to an Inquiry that happened here in New Zealand in the 1980's. An esteemed Medical Professor decided to undertake 'unapproved' (up for debate) research on thousands of New Zealand women (without their consent) and got away with it for 40 years – purely because his peers **let him**. His era (patriarchal) and the consequent fledgling Dr's taught over a 30-40 year period were taught his beliefs. Hundreds if not thousands of women's lives, wellbeing and fertility were affected and many died due to his belief that an abnormal cervical smear could **not** go on to cause Cervical Cancer. (The Cartwright Inquiry).

I am sure this can't be a one-off situation of people believing what they are taught and of a Medical Professional running amok, believing only they are right and everyone else is deluded? It is happening here in this Thyroid argument – with millions of women (thousands of men and children) who's lives, wellbeing, fertility and longevity are being held to ransom and played with. Knowledgeable and sympathetic Dr's need to feel that they won't be raked over the coals for prescribing T3 or Porcine T4/T3, which is happening world-wide – they are brought before councils and audited and must prove their patients need this treatment and are questioned as to the TSH being suppressed and other thyroid levels being out of the accepted ranges – some are censured, some struck-off. More research definitely needs to be done and good/best guidelines need to be drummed into new (and old) Dr's.

Test **all** thyroid hormones, especially free T3, trial patients on T3, test for antibodies and reverse T3, at the very least look at the whole person and how they present clinically (which is actually what Dr's are supposed to do) – not just at the Pituitary hormone TSH, scrap the 'hormone accepted ranges' and start again. Use the morning Basal body temperature as a diagnostic. TSH testing is such a **lazy**, unacceptable and dishonest waste of a client's time, money and life. Testing needs to be opened up without restriction until this is sorted out – and could give a good picture for future reference ranges.

I am hypothyroid and have been told it's Hashimotos disease, due to antibodies (though very low antibodies). My TSH is now suppressed and my previous GP look at this result and was visibly scared and confused – he said I had the opposite - hyperthyroidism (Grave's disease) – if he had looked at me and done a clinical diagnosis and not just my blood result – he would see (and I did point it out to him) I am taking replacement thyroid hormone (Whole Thyroid Extract)– so my pituitary can tell (via the feedback loop) I don't need any more so it is not producing Thyroid Stimulating Hormone (TSH) to stimulate my body to produce more T4 (my T4 and T3 levels were good, normal – not high). I don't have **any** hyperthyroid symptoms – I present clinically as hypothyroid. I do not have Graves antibodies....! He also told me the body takes as much T3 as it can to convert to T4 – this is completely wrong and the reverse - he did not even know the cycle of Thyroid hormone! There is something shockingly wrong with our medical teaching or lack of it. Natural instinct and logic have been erased.

What is this danger of a suppressed TSH, where are these recorded? If there is a true danger tell me what it is – I would rather live my life feeling well (even for a short time) – but at least give me the choice.

If there is some danger I would be well dead by now or have major problems/complications – wouldn't I? I take no other medication and I'm working fulltime. (I wasn't before changing from synthetic T4 to WTE and raising to an optimal dose). Why is it ok for women to be sick, not able to work, unable to drive, pile on the weight, unable to exercise, unable to think straight, be in constant pain or unable to have children – this is not normal! (nor are the other hundreds of possible symptoms that if looked at could lead to a diagnosis of Thyroid disease).

We females are sick (literally) of receiving the short straw in all areas of health. (though we do recognise this affects males as well). There is a huge lack of knowledge, understanding, funding, research, support and guidance with this area of all Thyroid and hormone disease.

You need the medical profession to work **with** advocates and sufferers such as Lorraine Cleaver to create new guidelines, best practice, and create new papers to be taught at medical schools to eradicate this abysmal deficiency within the health system, so we can all receive a correct diagnosis and treatment.

Thanks for taking the time to read this.

Jo Morris
Member of TANZI