

PE1463/VV

Petitioner Letter of 8 May 2014

Dear Convener and Members of the Committee,

As the sole petitioner, I regret that I am unable to attend the next petition committee meeting. On 20th May, my family will take our first holiday in ten years, a rare event due to years of ill health caused entirely by the shockingly poor thyroid treatment in this country. As you may know, I have now regained my health by singularly ignoring current medical protocols and evidence bases and by refusing the Levothyroxine that is standard NHS fare. I would love to be able to relax finally and enjoy my hard won health but am now in the desperate position of being unable to source my life saving Natural Desiccated Thyroid hormone. Previously I was able to buy this from a USA supplier without prescription but, as feared, the FDA have come under pressure from quarters undisclosed (though I suspect the UK) to demand prescriptions to ship to the UK. In three months I will have no medication so I intend to seek legal advice and challenge this. If I fail to source NDT, I will have no option but to withdraw the petition as my health will fail rapidly.

I am grateful for the many submissions in support of this petition, in particular that of Dr Midgley and Dr Hoermann who challenge the lack of evidence behind the British Thyroid Foundations pronouncements in their letter. I refuse to respond to their letter as they have refused to disclose the author. If they ever do reveal who wrote this, I will of course reply then. It's a basic courtesy to put your name to a letter as every other submission has done.

With regard to the Scottish Government's basis for refusing to carry out a Short Life Working Group, I can't say I am surprised they decided there was no evidence base as they asked the British Thyroid Association who are content to pronounce policy statements based on professional opinion rather than current evidence. As the late Dr Skinner said, "The BTA and Association of Clinical Biochemists support this pivotal reliance on Thyroid chemistry that has no evidential basis and was **never validated in proper clinical trial**". Dr Skinner forwarded these letters to the committee last year although they remain unpublished on the Petition website. The requested Scoping Report by Healthcare Improvement Scotland, despite asking the wrong questions, still found that "**UK guidelines for the use of Thyroid Function Tests published in 2006 were based on a non-systematic review of generally poor quality evidence from the United States (US) National Academy of Clinical Biochemistry (now archived)**". That ought to have been enough of a signal that there are major issues at the very early

levels of thyroid testing yet was clearly deemed unimportant or missed entirely. To say I am disappointed in the Minister for Public Health response is an understatement. This issue affects well over one hundred thousand women in Scotland and costs lives and untold sums of money. With that said, if this is the level of research that department carries out, perhaps it's not such a loss that the short life working group was refused.

Finally, I was delighted to meet with David Cline at St Andrews House to discuss the shape of the Listening Exercise. I believe there is a great opportunity for evidence to be gathered through out the intended year long project and would be happy to contribute in any way required. It was clear that Mr Cline grasped the true scale of the issue and the need for current evidence to be brought to the fore. I have every confidence in his department to carry out a useful and enlightening exercise.

In conclusion, I would urge the committee to continue Petition PE01463 to allow the Listening Exercise time to conclude and all new evidence to be submitted. There is a lot of research being peer reviewed as I write and this strongly challenges the current medical model. I am incredibly grateful to the committee for their time and patience in reading the complex evidence regarding this issue.

Sincerely,

Lorraine Cleaver
Petitioner