PE1463/RRRR
Petitioner submission of 12 December 2017

I wish to submit as further evidence a newly published article by Professor Anthony Toft, on what is almost exactly five years since the petition was lodged. Rather strikingly, Professor Toft echos what has been highlighted in the committee room by myself, by the retired co-petitioners Sandra Whyte and Marian Dyer, by Elaine Smith MSP, Dr John Midgley and the many others who submitted evidence in support of PE 01463. The article, Thyroid Hormone Replacement - A Counterblast to Guidelines, published in the Journal of the Royal College of Physicians Edinburgh last week, has been met with nothing short of stunned relief by the patients who have fought tirelessly to regain their health and to have doctors really hear and treat them. They are clutching on to it as a sign that things may eventually be about to change, particularly as NICE are about to begin work on thyroid disease guidelines next month. I fervently hope they are right. Sadly though, if five years of petitioning has taught me anything, it's that the pace of change in medicine and politics is glacially slow.

Professor Toft states "The facts of the matter are that the current guidelines for LT4 replacement therapy in primary hypothyroidism are not fit for purpose and the continued reluctance to approve additional treatment with liothyronine denies the patient the precision medicine which we are encouraged to adopt, and which many patients crave. In the future, D2 genotyping may play a role in identifying those patients likely to benefit from treatment with both thyroid hormones. In the meantime, I am so concerned about the state of advice on the management of primary hypothyroidism that I am increasingly reluctant to suggest ablative therapy with iodine-131 or surgery in patients with Graves' disease, irrespective of age or number of recurrences of hyperthyroidism. Treatment with a thionamide, in which the hypothalamic-pituitary-thyroid axis remains intact, making interpretation of thyroid status simpler, is currently a more attractive proposition. It is not that I am unprepared to disregard guidelines by prescribing 'a little too much' LT4 or combined thyroid hormone therapy, but I know that an increasing proportion of primary care physicians, advised by guidelines, will not accept my advice. Experience of managing more patients with thyroid disease than most over a period of some 40 years is being trumped by inflexible guidelines; truly a remarkable state of affairs. Others hide behind guidelines to avoid the cost of prescribing liothyronine, which in the UK is exorbitantly priced by the sole supplier at some £250 for two month's supply of 10 µg daily, when well-travelled patients can obtain supplies for a few euros in Italy and Greece and beyond."

I do hope this very recent statement is taken note of as it supersedes the evidence Professor Toft gave to the RoundTable meeting in October 2013 and certainly strikes an altogether more strident tone in favour of listening to patients, testing T3 and indeed, prescribing T3 where required.