

## PE1463/AAA

Petitioner Letter of 19 November 2014

Dear Convener and members of the Committee,

I was pleased to learn of the meeting you have scheduled with SIGN representatives on 25th November 2014 at the Petitions Committee and am hopeful that they will consider looking into writing Guidelines for the diagnosis and treatment of Hypothyroidism. However, there is huge potential for inadequate guidelines to cause further harm to the many thyroid patients who already struggle to obtain a diagnosis and suitable treatment and caution must be used when looking at evidence bases but particularly when only looking at guidelines for Primary Hypothyroidism. Cellular hypothyroidism is far more common than medics appear to be aware of and it's these patients who are being roundly ignored and neglected.

I have spent almost two years asking for evidence of the safety and efficacy of Levothyroxine as a treatment for Hypothyroidism. The MHRA, NICE, European Medicines Agency and Royal College of Physicians have to date provided none, even a Freedom of Information request drew a blank. Only this week I submitted a request via the Ask For Evidence website, run in association with Sense About Science, for evidence on the safety and efficacy of Levothyroxine as a treatment for hypothyroidism. This was directed at the Royal College of Physicians regarding their policy statement and the reply shocked me.

“The RCP’s guidance is based on the opinion of an expert panel which was temporarily formed for this purpose. The evidence they used to form their individual opinions has not been collated and therefore the RCP cannot provide an evidence list.” [Ask for evidence - Is levothyroxine safe and effective](#)

Just this month, a mother in England was released from jail and found not guilty of poisoning her daughter, charges brought after she took her daughter ‘doctor shopping’ to a world renowned European hormone specialist, Thierry Hertoghe for thyroid treatment the NHS in England failed to diagnose. This case is terrifying and has wider implications than just thyroid treatment guidelines, with parallels to the Ashya King story about freedom to treat outwith the NHS. Dr Hertoghe told the court that the NHS is 40 years behind in this area of medicine, treating only when the patient is 70% hormone deficient, whereas he and his colleagues would treat when the patient is 25% - 30% deficient. [Mother acquitted of poisoning in landmark case](#)

Ex editor of the BMJ Richard Smith wrote in an article titled **Medical Research - Still a scandal** of his concerns that many clinical trials and peer reviewed papers do not stand up to tough scrutiny yet evolve as Evidence Based Medicine [Medical Research - Still a scandal](#)

I urge the committee and SIGN to take particular note of the finding of Healthcare Improvement Scotland's scoping report on Hypothyroidism that the guidelines on the use of Thyroid Function Tests are based on 'generally poor quality, non peer reviewed evidence'

[http://www.healthcareimprovementscotland.org/our\\_work/technologies\\_and\\_medicines/shtg\\_scoping\\_reports/technologies\\_scoping\\_report\\_22.aspx](http://www.healthcareimprovementscotland.org/our_work/technologies_and_medicines/shtg_scoping_reports/technologies_scoping_report_22.aspx)

Dr Henry Lindner has previously submitted excellent evidence to back this petition and he is also of the opinion that much, if not **all**, of the previous clinical studies on diagnosing and treating hypothyroidism are based on bad science due to the mistaken assumption that the TSH reflects accurately what is happening at cellular level. "Current professional guidelines for the diagnosis and treatment of hypothyroidism abandon clinical medicine for a laboratory exercise : TSH and FT4 normalisation...The guidelines assume that almost all hypothyroidism is primary; that central hypothyroidism is rare and confined to persons with obvious hypothalamic- pituitary (HP) damage or disease. The guidelines thus assume that an anatomically intact HP system always functions perfectly to maintain optimal thyroid levels and effects. **No supporting evidence or argument is offered for any of these assumptions.**"

<http://hormonerestoration.com/files/TSHWrongtree.pdf>

With the above in mind, I really must stress that thyroid patients everywhere are, frankly, terrified that guidelines will further box us in to this hopeless treatment model where assumptions are made on unproven assertions and one medicine is touted as the over simplified solution to a complex endocrine disease. Scotland's NHS, much like the UK, has to face harsh budget realities but this is an excellent opportunity for the medical community to finally look afresh at the outdated and harmful way it has approached thyroid disease diagnosis and management and in reality, save enormous sums of money in wasted tests, erroneous diagnosis and lost tax revenues from patients left too ill to work. I am not overstating things when I say excellent guidelines will save lives.

Sincerely,

Lorraine Cleaver, Petitioner