PE1463/EEE

Dear Convener and members of the Petitions Committee,

Further to your kind request that SIGN consider guidelines for particular areas of thyroid diagnosis and treatment, I arranged a meeting with them to clarify the process and potential benefits to patients. This was prompted, in part, by an article in the Scottish press about conflict of interests with consultants working in an advisory capacity at SIGN committees, as well as the Scottish Medicines Consortium, particularly as these consultants are Endocrinologists and would be invariably called to assist with any thyroid guidelines. The outcome of that meeting was that I believe any guidelines formed on this basis will only cause further harm to a patient group already massively disadvantaged by the ‘one size fits all’ approach to a common endocrine condition and subjected to TSH tests which have never been scientifically validated.

After much discussion, a compromise was found that I believe will be more advantageous to patients and GPs. SIGN potentially can request a working group with the Royal College of GPs Scotland and stakeholders such as Thyroid UK, researchers and Endocrinologists to devise a type of updated ‘best practice’ document that will highlight the areas which are missed for patients with remaining symptoms on Levothyroxine, the so called 5% - 10% of patients. I am in the process of completing the proposals for this and will return them to SIGN as soon as they are ready. The time frame for such a project will hopefully be shorter than guidelines, although won’t begin until early 2017 in all likelihood and could take up to two years.

This being the case, I respectfully urge the committee to consider running their own inquiry, alongside the Listening Exercise the Scottish Government have undertaken. I cannot over stress how damning the results were of the excellent survey Thyroid UK conducted for the Scottish Government –

46% of respondents diagnosed with other conditions prior to hypothyroidism.
21% waited over five years from symptoms beginning until diagnosis.
21% are visiting their GP on a monthly basis due to continued symptoms, despite treatment.
40% of respondents have spent between **£500** and **£5000** visiting private GPs and Endocrinologists.

The cost to an already overstretched NHS Scotland is incredible. The fact remains that, despite the Royal College of Physicians updated policy statement of May this year, nothing has altered for patients who remain ill on Levothyroxine. Their statement makes absolutely no provision for those patients, up to **16%** of hypothyroid people on Levothyroxine. According to the American Thyroid Association –

1 woman in **8** will develop a thyroid disorder in their lifetime and women are **5 -8** times more likely than men to suffer from this. If up to **60%** are unaware of their thyroid condition and untreated, they are at risk for **cardiovascular disease, infertility and osteoporosis.**

As I've said before, this is a feminist issue as well as a health scandal. Women are being harmed on a grand scale and it's going unnoticed thanks to so called 'normal' TSH tests. After speaking with SIGN, it became clear it's not their remit to look into the licensing issue of Natural Desiccated Thyroid nor the non validation of thyroid blood tests. This former is a matter for the MHRA. I was advised the same by the European Parliament after I petitioned them. So where does that leave vulnerable Scottish patients with a devolved NHS but a reliance on licensing agreements in England? UK patients struggle to petition the UK government thanks to the requirement for 100,000 signatures and so it goes on, nothing changes.

I am again indebted to Elaine Smith MSP for raising a motion in the Scottish Parliament on thyroid disease awareness week last month and for her continued support for this petition, both as an MSP and as a thyroid patient. There is enormous gratitude within the thyroid community for the work the petitions committee have undertaken on this and I respectfully ask the convener to permit me a few minutes to speak at the next committee meeting in December.

Sincerely,

Lorraine Cleaver
Petitioner