

PE1463/PPPP

Petitioner submission of 15 September 2017

Reflecting on the previous evidence session in June, it's clear the problems within thyroid testing and diagnosis are so wide and over reaching that it's very difficult indeed for anyone to make progress. Unlicensed drugs are outwith the remit of the committee, I understand and accept that. However, there is one area which, if changed, could improve the lives of thousands, if not hundreds of thousands, of patients. That area is the guidelines for the use of Thyroid Function Tests.

As the committee will be aware, Healthcare Improvement Scotland produced a Scoping Report in to Hypothyroidism and 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 National Academy of Clinical Biochemistry (now archived).'**' Those guidelines stated they would be reviewed in **2009**. They were not.

I wrote to the Assoc of Clinical Biochemistry UK in June. They thanked me for bringing this out of date guidance to their attention and confirmed the matter would be discussed as a topic at their September meeting. When I followed this up, the response was

"The issue of maintenance and review of documents hosted on the ACB website was discussed at the Scientific Committee meeting on 1st September, and a decision was taken to escalate a recommendation to the Executive Committee.

The specific document was prepared by people who are mostly not now professionally active, so it is thought that it is unlikely to be updated. It may be removed or it may be kept on the website with a clear indication that it is now out of date and unlikely to be updated.

The minutes of committee meetings such as that on 1st September are for internal use only and not publicly available."

So we have out of date guidance written by professionals who no longer work in the field, with no intention of updating it. I cannot stress enough just how important this issue is. Telling GP's and laboratories which tests to conduct to diagnose and treat thyroid patients is absolutely **critical** to a timely diagnosis and adequate treatment. If these guidelines were reviewed and revised using the modern evidence base, it's very likely T3 tests would be advocated for patients on thyroid treatment and would expose the low levels of T3 many patients suffer on Levothyroxine (T4).

NICE begin working on Guidelines for Thyroid Disease on 19th September and I am attending the first scoping workshop in London for this. According to the briefing notes for this meeting, the issue of the quality of these 2006 guidelines is not being discussed. I believe Scotland needs to take the lead here and produce modern, gold standard guidelines for Thyroid Function Tests which will resolve in one fell swoop, the myriad issues of Thyroid diagnosis and Treatment.