

## **PE1463/PP**

Alex Hamper Email of 17 February 2014

Good Morning,

This is my submission in response to the British Thyroid Foundation submission regarding Petition PE01463. I wish this to be published as evidence.

The BTF submission mentions their Edinburgh BTF group meeting which I've attended a number of times. It is a good support group but there are plenty of people who attend that aren't on T4 only medication which is the only treatment the BTF currently advises.

The British Thyroid Foundation is a charity for sufferers of thyroid conditions but I would like to draw the attention of the committee to the fact that, for hypothyroid sufferers, it is currently only a voice for those who follow their current guidelines and take T4 only.

The British Thyroid Foundation stated that one of the three issues frequently raised by hypothyroid patients is that "treatment that does not achieve an adequate quality of life". Their response to that frequently raised issue appears slow. They've only just recently drafted a plan of action for further discussion with patients and medical advisors, which is at an early stage. In addition this plan doesn't even mention considering alternatives to levothyroxine.

Later in response to the petitioners asking for patients to be treated individually with T4 only, T4/T3, T3 only or natural desiccated thyroid they respond that: "We know that there are some patients who do not feel completely well on levothyroxine medication and we sympathise with this. However, there are issues with the solutions that the petitioners propose, and it is out of concern for safety and well-being of patients with hypothyroidism that we urge caution."

They do state the latest European Thyroid Association guidelines includes the "experimental" use of T3 alongside T4. They neither state that they agree or disagree with this which is unhelpful.

The BTF are aware that some patients are not well on levothyroxine but do not offer any advice on alternative treatments even though some patients in Scotland and the UK do take T3, on it's own or in combination with T4. The BTF actually acknowledges this on their website as they have chosen to publish a patient story where the patient improves significantly once T3 was added to her T4. As this has been publicly published on the internet I have included it for your reference at the end of this submission (ref 1).

While the petitioners request that T3 tests are used to diagnose thyroid problems the BTF "informs enquirers that these tests are not useful in the diagnosis of hypothyroidism. Our medical advisors inform us there is no reliable scientific evidence to the contrary." Yet some people have a conversion issue where they do not convert T4 very well into T3 in their bodies. The T3 test is the only way to diagnose these patients. If a T3 test is not done then thyroid issues will be ruled out and they will be given another diagnosis, often one that does not require a blood test like depression or M.E. I would again point out to the committee that while the BTF's statement says no to T3 testing the patient story on their website, that I have included for you, is from a patient that had a problem converting T4 to T3. So they acknowledge that some form of conversion problem exists for some patients but ignores this in their submission.

Their submission states that they are concerned by patients taking matters into their own hands and ordering T4 and T3 online. I personally am horrified by the fact that some sufferers are driven to such a desperate measure because they are not getting diagnosis or treatment by the NHS. As a hypothyroid patient my experience of the British Thyroid Foundation is that their grassroots members are very helpful and welcoming. So I am saddened that whoever wrote the BTF submission doesn't say they will investigate why some thyroid sufferers, which are the very people they aim to represent, are so desperate to order medicine online. Instead they try to tarnish the voice of those thyroid sufferers by suggesting that they are buying medication from sites selling drugs as slimming aids. I did go and find the correct link for the online drugstore they gave. The T4 and T3 is clearly sold as hypothyroid medication on that site and it specifically states that it should not be taken for weight loss or obesity problems.

I am somewhat at a loss to understand the thinking of the BTF in this submission, perhaps it would be best if, as the petitioner has requested, to know who wrote their submission. I am sure that the British Thyroid Foundation want the best for thyroid patients. I would have thought that as they had quoted one European Thyroid Association guideline they would have also pointed out to the commission that the ETA 2013 guideline for subclinical hypothyroidism differs from the current UK guidelines. The UK guidelines, which the BTF helped create, state that hypothyroid patients should be treated once their TSH reaches 10mU/liter. The ETA advise that patients under 70 who have a TSH of over 4mU/liter but under 10mU/liter and have symptoms that could be hypothyroid should be considered for a trial of T4 to see if their symptoms improve once their TSH is within the reference range. The UK guide of treatment at a TSH of over 10mU/liter is the highest I am aware of and I am equally aware that the American National Academy of Clinical Biochemistry found that 95% of normal individuals have a TSH of less than 2.5 mU/liter. However I should state that I am not advocating treatment for an underactive thyroid where the TSH is above normal levels but where there are no symptoms. It is a combination of

blood test results plus symptoms that should form the basis of a diagnosis. It is my hope that the committee will continue to investigate issues surrounding this petition and that the reference range used for diagnosis will be included in that.

Thank you for efforts in giving this petition the attention it deserves and enabling the voices of thyroid sufferers to be heard.

Best Regards,

Alex Hamper

Ref 1, British Thyroid Foundation website, Thyroid, Share Your Story, Angela, <http://www.btf-thyroid.org/index.php/thyroid/share-your-story>, accessed 11/02/2014.