

PE1463/NN

Julie Cameron Email of 14 February 2014

Dear Convener and the Ladies and Gentlemen of the Public Petitions Committee of the Scottish Parliament,

RE: PETITION PE01463

The three ladies who brought this petition to the attention of the Public Petitions Committee have shown great courage. It is no easy matter to put oneself under the spotlight but this is exactly what Sandra, Marian and Lorraine have done. They deserve an acknowledgement of their situation and the courtesy of a meaningful response from the medical authorities with whom they wish to engage via facilitation by the Scottish Parliament in order to resolve the issues raised by their petition.

So far, the majority of the written submissions have been in support of the petition as am I, but I do have some concerns with regard to the written submissions provided by both the RCP and the BTF. I would like to comment first of all on the response [or rather lack of response] received from the Royal College of Physicians. It consists of a paper on adrenals by Professor John Wass. As interesting as this paper is, I believe it shows that the RCP couldn't be bothered to respond specifically to the request for information from the Scottish Parliament in respect of this issue! I find this disturbing.

The second response on which I wish to comment is from the British Thyroid Foundation as I am concerned about several of the statements made. The BTF have stated, ***"It is understood that the majority of thyroid patients, including those with hypothyroidism, have their condition under control and do not seek change to their treatment or care"***. This is a sweeping generalisation and I would like to see the evidence which backs up this statement and ask also could the BTF answer the question, understood by whom? Furthermore, whilst it seems that some patients do respond in varying degrees to current treatments no-one to my knowledge actually knows the percentage of such thyroid patients, or even if they are in the majority.

The BTF then go on to say, ***"Nevertheless, we are aware that some patients with hypothyroidism are dissatisfied with their treatment"***. So here we have an admission that some patients do not feel that all is well with their treatment. Certainly the many thousands of patients who have signed the various petitions listed in my written submission published on the 16th of January 2014 [PE1463/FF] suggests that there is a great deal of dissatisfaction and discontent amongst hypothyroid patients.

The BTF then pass comment about those who are dissatisfied with their treatment as follows, ***"We note that such patients are self-selecting, and may be more likely to contact thyroid patient organisations for information, advice and support than those who feel well on their treatment regime."*** So here is another question for the BTF. What do they mean by self-selecting? I am unsure what is meant or

being implied here! However, the BTF, then go on to list the issues raised by such self-selecting hypothyroid patients as follows:

“The issues raised by hypothyroid patients frequently focus on concerns about:

- ***treatment that does not achieve an adequate quality of life***
- ***communication problems with doctors, usually GPs, and***
- ***perceived inaccurate diagnosis”***

With respect, the above list appears to be minimising the number of problems being faced by such patients and I can add to this list of concerns by hypothyroid patients:

1. Failure to diagnose hypothyroidism
2. Under treatment of hypothyroidism
3. Failure to optimise treatment for each individual patient
4. GPs or endocrinologists not listening to the patient
5. Actual misdiagnosis of hypothyroidism resulting in unnecessary referrals elsewhere
6. Lack of choice of medication – virtually unheard of for any other disorder
7. Readiness to prescribe anti-depressants, yet reluctance to provide a trial of thyroxine
8. The issues raised by the petitioners within PE1463
9. The questions already put to the RCP, BTA, BTF et al in my written submission dated 22nd March 2013 PE1463/CC refers, questions which have to date never been answered.
10. The wording of the various petitions/campaigns PE1463/FF refers, where numerous concerns are given in the petition titles themselves
11. Concerns with TFT testing, particularly signs and symptoms that do not correlate with blood test results.
12. RCP/BTA/BTF et al endorsement of monotherapy i.e. the one size fits all approach.
13. Differences in TFT reference intervals from country to country
14. Difference in TFT reference intervals depending on where you live in the UK
15. Differences in TFT reference intervals between different laboratories.
16. Over reliance on blood test results
17. Patients not being treated on an individual basis despite the fact that each individual will require different treatment to optimise recovery from symptoms
18. The fact that many thousands of patients subscribe to various Thyroid support groups because they cannot find the answers they seek from within the NHS.

So, is this just tip of the iceberg? Interestingly, I cannot see any evidence of any discontented patients on the BTF website, which is perhaps why the BTF [and the BTA, to whom they are strongly affiliated] might wrongly assume that this is a ‘small’ problem. Whereas, from the above evidence it would seem that on the contrary, it is a “huge” [worldwide] problem and it needs to be addressed.

Of course, there are some remarkable doctors who have successfully treated such patients, turned lives around and saved lives. Notably the late Dr Gordon Skinner, an exceptional Scottish doctor, who listened to his patients, discovered the causes of

their signs and symptoms [in many cases hypothyroidism] and successfully treated over 5000 such patients using a range of treatments, see "Tribute to Dr Gordon Skinner" on www.worldthyroidregister.co.uk for confirmation of this. It also needs to be noted that each of Dr Skinner's 5000+ patients would have been seriously ill when referred to him by their GPs, so this suggests that every one of these patients had been previously failed by mainstream guidance and this in turn implies that some of the answers are already there and need to be formalised as part of an "action to ensure that GPs and endocrinologists are able to accurately diagnose thyroid and adrenal disorders and provide the most appropriate treatment," as specified by the petitioners.

The petitioners are therefore to be applauded for bringing about this petition. An enquiry is urgently needed into why patients like the petitioners and thousands of others have been allowed to suffer for so long. An opportunity must now be provided for any patients who have experienced such problems to be involved in this enquiry and investigative process together with individuals and other health professionals who hold other viewpoints from the mainstream. This is not an insurmountable issue and I trust that the Scottish Parliament will take this petition forward and I respectfully submit the above as a written submission to the members of the Public Petitions Committee.

Yours sincerely,
Mrs Julie Cameron MBA
14th February 2014