

PE1463/Z

Susan Flack Email of 7 November 2013

Dear Sir/Madam,

Scottish Parliament Petition number PE 1463 –
Effective thyroid and adrenal testing, diagnosis and treatment

I watched the Scottish Parliament Round Table Discussion held on 1st October 2013 with great interest and alarm. Most of the time seemed to be used by official bodies backing up their official guidelines. The FACT that the petitioners and many others have, with a huge struggle, found answers and greatly improved health by moving to Private Health Treatment or Self Treatment seemed to have been missed. It does not matter how many studies have been carried out; we are living proof that huge suffering can be eliminated with the correct treatment.

Dr Anthony Toft, present at the meeting, conceded that there is some evidence that some patients need Liothyronine (T3) in addition to Levothyroxine (T4). (He refers to this in his book 'Understanding Thyroid Disorders' (2008), page 46.) He believes that the number who need T3 is low. He started to defend his view by saying something like 'I know because in hospital we monitor them.' (He was then cut off.) My response to this is that patients with hypothyroidism should not be going into hospital. They should be being diagnosed and treated properly by GPs. Also, how are they monitored? Are the same two blood tests (TSH and Free T4) used? Are all their symptoms and signs being taken into account?

At one time the 'new' sensitive TSH test was thought to be the only test required to monitor thyroid problems. This was being discussed when Dr Toft said something like 'that was my fault but I was soon told the error of my ways'. (Someone else called out "can we have that in writing?" The meeting was then moved on.) The point here is that a distinguished and qualified person, at the head of a very powerful organization, can influence the welfare of so many and BE WRONG.

The Public need a voice that is listened to and this applies to every area of the NHS including hospital care as well as all other areas of life. The Scottish Parliament could break new ground by setting up a Web-site to cover this need. There has to be a balance to the enormous power the medical associations hold.

Thyroid patients want some simple tests, with proper interpretation, and informed notice taken of signs and symptoms. It seems that Doctors are not trained to understand that 'Normal' ranges cover about 95% of the population AND EVERY ONE IS DIFFERENT. OUR 'NORMAL' IS PROBABLY AT ONE PARTICULAR

POINT ON THE SCALE AND WHEN WE GO ABOVE OR BELOW IT WE ARE NOT WELL, EVEN THOUGH WE ARE 'WITHIN RANGE'.

The treatment we are asking for would benefit so many people and save the NHS money. There are many people who are misdiagnosed. (I know this from personal contacts as well as people on Web forums). Others feel awful but cannot find out what is wrong with them. People go through the expense and pain of fertility treatment or suffer repeated miscarriages when all that is needed is proper treatment of the thyroid gland. Others are sent for a string of expensive tests and consultations when some simple tests and proper training is all that is needed.

Suffering with this malady is painful, extremely upsetting (the loss of mental faculties and the responses given by GPs and others) and financially disastrous. In some cases it is fatal. Trying to fight for proper treatment when feeling this ill is a struggle many give up.

Please Committee, DO NOT LET US DOWN. It could be you or a loved one that is hit next.

Susan Flack