

PE1463/AAAA

Anonymous Submission of 10 February 2016

Dear Petitions Committee for Thyroid Petition PE01463

I am writing this in support of Lorraine Cleaver and Thyroid Petition PE01463

Thanks to the Internet, it is apparent to patients around the world that the treatment (or lack of) thyroid disease is a worldwide problem. I am from Canada and I have had thyroid cancer. And like many thyroid patients, I have been following the story and efforts of Lorraine Cleaver and her Petition PE01463 with interest and great hope.

To offer a little “anecdotal” evidence:

As it turns out, my thyroid disease background is pretty typical. I began to feel ill in my 30's and was told I was getting old and to get out more. By my 40's I was experiencing cognitive problems, hair loss, weight gain; all the typical hypothyroid symptoms. However, upon describing these symptoms to my Doctor, it was insinuated that it was “all in my head” and I was dismissed.

Tired of the cruel attitude of my Dr, my husband and I took a large part of our savings to The Cleveland Clinic, which you may be familiar with, as it is quite famous. We paid a lot of money to meet with a real doctor who immediately (and I do mean immediately) recognized my thyroid disease. His findings however, also showed that it had progressed to thyroid cancer. This was 2004.

Finally diagnosed, but out of money, I had to rely on the free Canadian health care system to remove my thyroid and provide continued treatment. 12 years later they think I am completely well on my T4 medication; the picture of health, as it were.

The truth is, my symptoms, and a few new ones, continued for years. It was through people like Lorraine Cleaver and various independent thyroid support sites that empowered me to try to regain my health all on my own.

To do that, I have been forced to go behind my endocrinologist's back. Thankfully, natural thyroid hormone is available in Canada, but is not allowed to be prescribed by doctors in our free health system (presumably because of contractual obligations with pharmaceutical interests). So now, I pay a naturopathic doctor for visits and monitoring blood tests. My endocrinologist does not know and I can't tell him because I need to keep the door open for more unaffordable costs such as my ongoing need for ultrasounds to monitor for cancer recurrence, which only he can order.

By the way, my endocrinologist is a professor at a large Canadian university. He is vehemently opposed to the use of NDT and has told me himself that “NO one needs T3”. He has, or has had ties to Eli Lilly, GSK, Merck, Novo Nordisk, Sanofi-Aventis, Ortho Janssen. So that's the future of thyroid endocrinology here.

By taking matters into my own hands, I have regained much of my health on natural desiccated thyroid, I have lost weight, my blood pressure and cholesterol are improved and I can get to my doctor appointments without getting lost on the way (because now my thinking is clear). Best of all, my free Endocrinologist is really nice to me because I no longer complain to him. He probably thinks he's a great doctor too - everyone is happy!

I watched the video of your February 9 meeting of the Petitions Committee with your Minister of Public Health and Prof. Leese. But it seemed pretty obvious that Dr. Leese and Ms Watt had little interest. They didn't want to be at that meeting. They were unprepared for and resented having to answer your questions. They were certainly annoyed by the whole ordeal. It occurred to me that their mandate was actually quite different from yours; it was as if they thought they were there to easily squelch an uprising and then go back to business as usual.

As I watched the video, I found myself wondering how many of Prof, Leese's patients are at this moment, working behind his back to make themselves well and to make him feel like a great doctor. I guess we will never know... but it would be an interesting question for the next survey.

All in all, I just want to offer my support and hope that you are able to continue this petition. In Canada, we have no way of initiating the kind of process Lorraine has been able to do in Scotland. I envy you the ability to pursue a solution to this grave injustice.