

PE1463/FF

Julie Cameron Addendum to Letter of 22 March 2013

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

RE: PETITION PE01463

Thank you for accepting as written evidence my letter dated 22nd March 2013, in full support of Petition PE01463 and for publishing it on the petition web page. Further to this, I have compiled a list of campaigns/petitions/attempts by the 'hypothyroid community' to raise awareness of our concerns with the medical authorities, which I should also like to submit as written evidence to the Petitions Committee.

LIST OF THYROID RELATED CAMPAIGNS/ PETITIONS [I have provided direct links]

PETITION SUBMITTED TO THE GMC AND VARIOUS MEDICAL ESTABLISHMENTS [2005]

This is the first petition of which I have knowledge. It was begun by Diana Holmes and was couched as a 'formal complaint against the clinical practice of the majority of the medical profession with regard to the diagnosis and management of hypothyroidism on four counts' [these were specified within the petition] It was presented to the GMC in person by Diana and copied to numerous other medical establishments. It had 3000+ signatories. For more information, you would need to go to 'Thyroid Petition for United Kingdom – Developed by Diana Holmes' at <http://thyroid.about.com/library/weekly/blukpetition.htm>

PETITION SUBMITTED TO THE NATIONAL ASSEMBLY FOR WALES [NAfW][2008]

This was fronted by Dr Sarah Myhill on behalf of hypothyroid patients and I was involved as the petition co-ordinator. The petition called upon the NAfW to investigate the non-diagnosis and mismanagement of hypothyroidism in Wales with a view to producing recommendations to rectify the situation. 1433 signatures were submitted. For further information and to see the completion report, go to http://www.assemblywales.org/completion_report_p-03-137_e.pdf

I think it worth mentioning here that this completion report shows responses from the medical profession only – but no details of the mass of information [including scientific information] sent in by the petitioners and other hypothyroid support organisations, nor was an opportunity provided to present our case in person.

WORLD THYROID REGISTER [AROUND 2009-2010]

Begun in the UK by Dr Gordon Skinner, the register seeks better care for thyroid patients, to date it has 5346 signatories plus approximately 40,000 affiliates. Go to www.worldthyroidregister.com and click 'UPDATES' to see details of signatories, then click 'AFFILIATES' which shows the affiliated memberships, including those in the UK, USA, Europe and the Peoples' Republic of China. Sadly Dr. Skinner passed away on the 26th of November 2013.

INTERNATIONAL HORMONE SOCIETY THYROID PETITION [PRE 2011]

This petition was compiled on behalf of hypothyroid patients worldwide by Sheila Turner of TPA-UK, Susanne König [France], Sabine Seichter [Germany], Lyn Mynott of ThyroidUK and Janie Bowthorpe of stopthethyroidmadness [USA]. It was entitled, 'Patients Petition for the Better Diagnosis and Treatment Choice for Hypothyroid Patients'. By 2011 it had around 2000 signatures. For more information go to Patients Petitions, Consensus 1 at www.intlhormonesociety.org

THYROID CHANGE [2012]

Begun in the USA by Michelle Theresa and entitled, 'Endocrinologists: Patients with Thyroid Dysfunction Demand Better Care,' it has 15,803 signatories to date. To see the website and for access to the petition please visit www.thyroidchange.org.

BEST PETITION [2013]

Set up via the 38 degrees group by Diane Bamford, this petition is entitled:- Better Endocrinological Services and Treatment for Thyroid Patients [BEST]. To date this petition has 3,375 signatures. Go to www.thyroiduk.org.uk click 'CAMPAIGNS' on the left of the screen and then click onto the UK petition shown above (B.E.S.T) for access to further information and the petition.

WHO PETITION

Set up by a hypothyroid patient and entitled Better Treatment for Hypothyroidism, it was intended that this petition be delivered to the World Health Organization. To date it has 420 signatures. For more information go to www.avaaz.org/en/petition/Better_treatment_for_hypothyroidism/

E-PETITION

Started by Lyn Mynott of ThyroidUK, this petition requests that the UK government fund research into T3 and/or Natural Desiccated Thyroid. This petition which recently

closed had 5215 signatures. Go to www.thyroiduk.org.uk and again click 'CAMPAIGNS' and scroll to bottom entry to see more detail on this e-petition.

REGISTER OF COUNTER EXAMPLES

Set up by Sheila Turner of Thyroid Patient Advocacy [TPA-UK]. The purpose of the list is to register counter examples to T4 only therapy by means of a questionnaire which hypothyroid patients can complete. The register provides numerous examples of hypothyroid patients who do not do well on T4 only. This has 2469 signatures at the time of writing see www.tpauk.com and click on 'articles' then scroll down to TPA WORLD THYROID REGISTERS for further information.

SCOTTISH PARLIAMENT PETITION

Lodged in December 2012 by Lorraine Cleaver, Sandra Whyte and Marian Dyer. Judging from the written evidence already submitted, there is much support for this petition and the world hypothyroid community is watching, waiting and fervently hoping for a positive outcome to this petition for hypothyroid sufferers everywhere.

The above list is by no means comprehensive [there are many other related petitions/campaigns out there] but regarding the above, the number of signatories/affiliates add up to almost 80,000. So if according to the medical profession and endocrinologists all is well with the treatment of hypothyroid patients - then why this continuous outpouring of dissatisfaction? The unnecessary suffering of hypothyroid patients [be it via non-diagnosis, misdiagnosis, under treatment or incorrect treatment and limited choice of treatment to name but a few of the things that are currently happening] needs to be urgently investigated. I firmly believe that the Scottish Parliament will not let us down and will support this petition and take appropriate action to address the issues raised by the petitioners [Not just for Scotland but the World]. I hope the above information is useful.

Yours sincerely

Mrs Julie Cameron MBA
30th December 2013

PS: I have already made the above information known to Elaine Smith MSP and the 3 petitioners: Lorraine Cleaver, Sandra Whyte and Marian Dyer, albeit in a slightly different format. The petitioners with my permission placed it on their 'Facebook' page. As a result of this, links to a further 3 current petitions of which I had no previous knowledge had been added there as follows:

NORWAY, 1426 signatures to date
SWEDEN, 1267 signatures to date

FINLAND, 6504 signatures to date. Text in English below
http://www.adressit.com/vastustamme_valviran_aikeita...