

PE1463/DD

Petitioner's response to October 1st Round Table meeting PE01463

19th December 2013.

Dear Convener and members of the Committee,

It has taken us many weeks to be able to formulate a response to the above meeting, such was our shock at the attitude of the professionals who attended. There seemed to be lengthy discussions on how the thyroid works but far less on how to put it right when it malfunctions. We take particular issue with Professor Williams' comment, "I do not think there is a place at the moment for T3 because we do not understand enough about it." Well there was certainly sufficient understanding of it in the 1950s when President John F Kennedy was prescribed it twice daily for his hypothyroidism.

<http://articles.latimes.com/2009/sep/05/science/sci-jfk-addisons5>

Quite how much longer does the endocrinology speciality require to learn 'enough about it?'

Professor Williams also states "For example, if you have a patient who is on T4, they will convert T4 to T3 in the periphery..." That is in a perfect world and that does not always happen, in fact it commonly does not happen which is almost the entire point of our petition! The endocrinologists say that it's rare for this non conversion (yet refuse to provide evidence of such claims) but it may only appear rare because they refuse to test for this. Absence of evidence is not evidence of absence. The many thousands of patients who complain of symptoms whilst on T4 only medication are not having FT3 tested, a better indicator of what T3 is available to the cells.

When Professor Williams answers Chic Brodie's valid question about any downside of prescribing T3, he says "In my opinion, the downside would be that there would be a tendency...to prescribe T3, because the level would be seen to be below the reference range." The reference range is there for a reason, and to be below it is not good or healthy for patients. If testing for high FT3 in hyperthyroid patients is accurate enough to give an indication they are over active, as Professor Toft agrees, then it is logical that the test works in reverse, as a good enough indicator of insufficient FT3 for the tissue. Professor Williams then goes on to list the pitfalls of prescribing too much T3, when no one is advocating too much of anything, merely replacement of deficient hormones to the normal healthy level, the supposed role of an endocrinologist after all. Perhaps

Professor Williams' comment about too much T3 is related to the British Thyroid Foundation's submission, the charity he is a trustee of. In that submission, they link to a website selling T3 medication under the heading 'weight loss' albeit their link does not work. This truly is a puerile insult to suffering patients and we will respond to the British Thyroid Foundation's submission separately when they finally answer our question as to who wrote their paper. We do however query Professor Williams' statement that the British Thyroid Foundation have 20% of their membership in Scotland. The British Thyroid Foundation themselves say it is closer to 10%, and 10% of just over 4000 members is far less than the Scottish members of Thyroid UK.

Professor Toft offered to answer the petitioner's question as to whom the RCP were accountable to and why the health of so many was in the hands of a charity. He didn't actually answer this but stated who made guidelines, usually the specialist societies, for example the Society for Endocrinology. This matter needs to be clarified we feel. If the RCP, Society for Endocrinology and indeed the GMC are not answerable to the Department of Health of Government, just exactly who are they answerable to? Patients need clarity here because charities seem to wield enormous power.

The decades long dissent in the treatment of hypothyroidism shows little sign of ending and the patient is still suffering greatly. This study from 1952 comparing treatment with desiccated thyroid and Levothyroxine shows starkly how the argument has not moved forward. "It seems obvious therefore that during treatment of hypothyroidism with thyroxine, the serum P.B.I.(protein bound iodine) may reach a high level indicative of thyrotoxicosis when no such condition is present clinically, and that a more accurate indication of clinical status is provided by B.M.R. (Basal Metabolic Rate)

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2023211/?page=1>

The good doctors who still treat the patient according to clinical signs, as well as blood results, are being hounded by the GMC. Many thousands of patients were devastated to learn of the untimely death of Dr Gordon Skinner on 26th November from a stroke. He was called before the GMC many times and had restrictions on his fitness to practice at the time of his death, with all the stress this brought to him. Dr Skinner's death provoked an outpouring of grief and gratitude for his service to hypothyroid patients and he was a credit to Scotland. To spend his final years having to answer the GMC for healing his patients is shameful and that shame is not his.

Why are endocrinologist still debating the use of T3 and FT3 tests? Why are they keeping us ill while good doctors like the late Dr Skinner were healing us yet being punished for doing so?

<https://www.endocrine.org/news-room/current-press-releases/low-thyroid-levels-may-signal-heightened-risk-of-death-in-hospitalized-patients>

The current petition of Dr Peter Gordon calling for a Sunshine Act for Scotland is very timely and links to what we ask here. The fact is, medical education is funded partially by pharma and so there are vested interests. We posit that there is an interest in keeping hypothyroid patients unwell, as we become huge consumers of further medications, polypharmacy. There is evidence, previously submitted, that we go on to develop heart disease and diabetes. Diabetes care in Scotland is partly funded by the drug manufacturers. This may be common practice within the NHS Scotland now but that does not make it right. If private drug companies have such sway within the NHS, it could be said they have an interest in increasing their patient pool.

John Ioannidis, at the Seventh Peer Review Congress in Chicago said “Most scientific studies are wrong, and they are wrong because scientists are interested in funding careers rather than the truth”

<http://blogs.bmj.com/bmj/2013/09/09/richard-smith-time-for-science-to-be-about-truth-rather-than-careers/>

The systemic corruption of medical knowledge, ranging from clinical trials and new diagnostic categories through practice guidelines to physician prescribing practices, is highlighted in a special fall issue of the Journal of Law, Medicine & Ethics (JLME, 41:3)

http://www.law.harvard.edu/news/2013/10/25_edmond-j-safra-center-for-ethics-fellows-jlme.html

Glasgow GP, Dr Des Spence writes, “Educational sponsorship is about controlling the medical agenda and endorsing a blind, therapeutic mindset. It is free medical education sponsored by pharma that has helped spawn overtreatment, polypharmacy, medicalisation and high costs.”

<http://bad4umedicine.blogspot.co.uk/>

We believe medicine needs to clean up its act and that it's not sufficient for ministers to assure us that health agencies, whether charities or otherwise, are looking at peer reviewed evidence when making treatment decisions.

We note that Novo Nordisk, manufacturers of diabetic insulin, awarded their Jacobaeus Prize in 2012 to British Endocrinologist, Professor Anthony Weetman. This is the same

endocrinologist who declared that many hypothyroid patients are suffering from somatoform disorder. This is medical speak for 'it's in their heads.' This company work closely with the Scottish Government and departments of health, providing diabetic training and care widely across Scotland. "Partnership with the pharmaceutical industry can provide access to skill sets and training that can help the successful implementation of the diabetes action plan. These could include marketing, business planning, project management and team working. Novo Nordisk already offers and delivers some of these services to our customers in Scotland." Also from this document, " Novo Nordisk will support more training and education for medical staff on the wards, and this could be an area for increased partnership with the pharmaceutical industry."

<http://www.scotland.gov.uk/Resource/Doc/318403/0101594.pdf>

We believe our human rights are being denied. As the European Convention on Human Rights states. "The freedom to accept or refuse specific medical treatment, or to select an alternative form of treatment, is vital to the principles of self-determination and personal autonomy." From the same document, "(Article 2, European Convention on Human Rights [ECHR]) include: A positive obligation on the State to do "all that could have been required of it to prevent the applicant's life from being avoidably put at risk" in health care,19

<http://www.scottishhumanrights.com/application/resources/documents/SNAP/GettingitRightAnOverviewofHumanRightsinScotland2012.pdf>

We are encouraged that today, National Human Rights Day, Scotland's National Action Plan for Human Rights (SNAP) is published, with particular emphasis being place on health.

In no other scientific discipline would measurement tools of such variability be allowed. The producers would be laughed to scorn and wouldn't last two minutes. Abrogation of responsibility all round and the patient suffers as a result. A final quote from Professor Williams, "I do not think we are too far apart. We need to work together rather than be adversarial." We sadly have found this to be far from true. We are indeed miles apart whilst the speciality deny the scale of conversion problems. Endocrinologists are very dismissive of ongoing symptoms, refusing even to be adversarial. We need proper action now, a serious overhaul of thyroid disease management as the current system is broken. Patients worldwide are now galvanising and lobbying their Governments because of petition PE01463. Scotland has a great opportunity here to lead the way and make great strides to improve the health of many thousands, saving huge sums of money on ineffective and unnecessary medications. It can do this by grasping the

enormity of what we are saying, that there is too much pharma intervention in medicine, that there are conflicts of interest and that patient's human rights are currently being denied. We recognise that this is an enormous ask for a large scale problem but it is not insurmountable and if anyone can solve this, Scotland can.

“All men make mistakes, but a good man yields when he knows his course is wrong, and repairs the evil. The only crime is pride.”— Sophocles, *Antigone*”