Mid-Summer Newsletter
Special Edition
July 2010

New Questionnaire for World Wide Register of Counterexamples to T4-only Therapy

I apologise for the great confusion many of you experienced in trying to answer three short questions in the survey we set up online, in order to help us create the FIRST world-wide Register of Counterexamples to Levothyroxine Sodium-only Therapy. We had 108 responses to date, and about as many other members telling me they could not complete it because they didn't know how to answer. Many thanks to all who did write to me pointing out the confusing issues, because this saved me sending it out world-wide, which would have proved a waste of our time and effort and the project would have got nowhere. Embarrassment all round.

You will be pleased to hear that the original questionnaire has been changed and the 'old' version has been removed from the web site, so apologies to those of you who had already completed it, but will you now go to our new link and complete this one. Please clear out any cached versions you may have, otherwise, this will cause confusion for you again. You will find the revised questions are easily understood so you should have no problem in giving a simple YES or NO response this time.

PLEASE NOTE that this questionnaire is **ONLY** for those people who were prescribed a T4-only containing thyroid hormone replacement and who fared badly because they continued with symptoms of hypothyroidism but who then tried a T3 containing hormone replacement (Liothyronine/Cytomel/natural thyroid extract), either officially prescribed, or purchased from Internet pharmacies or elsewhere, and your symptoms got better. The revised questionnaire – currently available in **English, Danish, and German** – can be found at the following link: http://www.tpa-uk.org.uk/register_of_counterexamples.php. The remaining languages will be available soon.

IT IS VERY IMPORTANT THAT ALL WHO HAVE TAKEN T4 AND T3 SHOULD COMPLETE THIS IF WE ARE TO CONVINCE THE MEDICAL BOARDS THROUGHOUT THE WORLD THAT LEVOTHYROXINE ALONE DOES NOT WORK FOR EVERYBODY AS

THEY WOULD HAVE US BELIEVE. There has never been such a world-wide register before, this is a FIRST and this is the one thing that might finally convince the BTA and RCP et al in the UK that they are wrong, and, at last, <u>have been proved to be wrong</u>....but only you can help us!

If you have not already done so, please sign the Hypothyroid Patient's Petition for a better diagnosis and treatment protocol (with a choice of treatment) Petition on the above World Wide Register Form.

The Government Spending Challenge: Help Us Get More for Less

You are no doubt all aware of what has happened over the past few days to our previous idea(s) and comments that were submitted via the Government web site asking for our ideas on how we see they could save money and our ideas on how they could do this. On no less than three occasions, we have had all our original message 'HYPOTHYROIDISM - URGENT PUBLIC ENQUIRY CALLED FOR', plus all the many comments with the five-star high ratings removed. No one from the government, the administrators or the moderators have yet responded to our requests when asking them for an explanation. For all those who wrote the original idea and those who wrote comments, we found our password, username and now, it appears, our IP numbers blocked so none of us could gain access to the Spending Challenge web site anymore.

We are still investigating what happened and hope to get an answer soon, but meanwhile, because of the problems, we are all being given another chance (I think!!!!) as they are now asking us to complete an online form, and will take the most suitable ideas into consideration. Be sure that you read their information before writing and write it in the way they have requested **http://spendingchallenge.hm-treasury.gov.uk/?PRO=sc&CRE=rhm** . You can all go to this link and give your idea - but these will NOT be followed with further comments or star ratings, but if they get enough comments about how badly those suffering with the symptoms of hypothyroidism are treated by the NHS and how many millions of pounds could be saved if patients were diagnosed and treated correctly, the more chance our 'ideas' will attract the attention of the Chancellor.

PLEASE NOTE: This is very important. We have never before had such an opportunity to approach the government directly with our problems. We must make them listen and realise how many millions of pounds (and millions of lives they could save) if they

started listening to those suffering as well as the Royal College of Physicians and the British Thyroid Association, et al.

If any of you would like some ideas, take another look at my original message to the Chancellor as this may help you. You may wish to expand on some of them with your own ideas. You can find my original message in the FILES SECTION of the forum web site or go directly here:

http://f1.grp.yahoofs.com/v1/8FRBTGFceHOv7dnuq8hYN9OHRqnRGVvs7ZWtgkAh5TD66T08R7DY_oRAzgC8JhfoBzqDWrlfkkKOJp7m2ClapQ/IDEA%20FOR%20GOVT.%20TO%20SAVE%20MONEY.doc .

Please pass this new link onto everybody you know, including Twitter, Facebook, other thyroid groups etc.

Dr Gordon Skinner's World-wide Thyroid Register

As you are aware from our Spring/Summer TPA Newsletter, Dr Gordon Skinner is in the process of creating the worlds first THYROID REGISTER which needs the support of each and every one of us. It can be accessed via the following link: **http://www.worldthyroidregister.com/** and the covering letter says it all. Please think about signing it and passing this email or newsletter (whichever you are accessing) on to all your family, friends, and contacts so that they each have the opportunity to sign it too. Again, I cannot emphasise the importance of signing this.

PLEASE DO NOT DELETE THIS SPECIAL EDITION MINI-NEWSLETTER UNTIL YOU HAVE DONE WHATEVER YOU CAN TO HELP YOURSELF AND YOUR FELLOW SUFFERERS. It is only by each one of us doing our little bit (which will take perhaps five minutes of your time) that we are going to make a difference.

FINALLY: If you are wanting to attend our next TPA Conference to be held in Birmingham (details in the last newsletter: (**http://www.tpa-uk.org.uk/newsletters/newsletter_june10.pdf)** to be held on Saturday, 2 October and you have not yet booked a place, please let Amanda **Galathea@tiscali.co.uk** know if you will be attending and how many guests you will be

bringing with you. We can only seat 130 and places are already being snapped up. The meeting starts at 12.00 noon sharp with lunch, to be followed by speeches from Dr Peatfield, Dr Skinner and Dr Mantzourani.

We will again be holding a raffle once again for prizes donated by some of our members, so if you would be happy to donate something, please will you contact Marie **holloway.marie@googlemail.com** and let her know. At our April conference, our raffle raised over £400 for TPA which was wonderful. Many thanks to all who contributed.

Many thanks,
Sheila and Lee
www.tpa-uk.org.uk

Hypothyroidism: Urgent Public Enquiry Called For

If the RCP and BTA started listening to patients with hypothyroid symptoms, millions of pounds could be saved. This could **ONLY** be achieved by the Government calling for a Public Enquiry to investigate why sufferers are being refused a proper diagnosis and/or a choice of thyroid hormone replacement.

The problem is a political and/or legal problem. It is not merely a medical problem. There are patients who are counterexamples that negate the dictates promulgated by the RCP, BTA et al. Adherence to these dictates by doctors results in patient abuse.

Sufferers are being denied a proper diagnosis because of the excessive ‘normal’ reference range of serum thyroid stimulating hormone (TSH). They are suffering because of the seriously flawed 'Guidance on the Diagnosis and Management of Primary Hypothyroidism' that tells doctors they should not give a diagnosis of hypothyroidism if a patients' serum TSH is within the reference range of 0.5 to 10.0uM/L.

This reference range is so wide as to be unmatched by every other country. Many countries have realised their previous TSH range was overlooking patients and agreed it should be narrowed. The AACE recommended TSH range be lowed from 0.5 to 5.0 mU/L to 0.3 to 3.0mU/L. In Germany, Belgium, and now Sweden, it has been lowered to 0.3 to 2.5mU/L., with a recommendation by Belgium that the upper limit be dropped still further to 1.5mU/L. Since America dropped the upper level of their range from 5.0mU/L to 3.0 in 2003, by 2005 over 13 million additional sufferers had been given a diagnosis of hypothyroidism.

For those given a diagnosis, the RCP ‘guidance’ (effectively mandatory) recommend treatment with levothyroxine (T4) **ONLY** and that triiodothyronine (T3), (the **ACTIVE** thyroid hormone), synthetic or natural, should not be used. T4 is a pro-hormone that must convert to T3.T4 appears to work for many, but for a large minority, they are unable to convert T4 to T3. It is in every cell in the body and brain needs T3 to make them function – NOT T4.

The BTA and RCP are boycotting all T3 products. T3 is vital for life. Medical science showed this over 40 years ago, yet they refuse to acknowledge this fact.

There are many patient counterexamples to the T4-only therapy. Patient counterexamples are those who fare poorly under the medical prescriptions (T4–only) and fare well under the medical proscriptions (T3). These counterexamples demonstrate that there is no medical problem - only a political or legal problem. Consequently, the endocrinologists are WRONG. Without T3, we die. The proscription of T4-only is illogical and unethical. It has counterexamples amongst testifying patients and in peer-reviewed medical science journals.

I MUST stress the pernicious involvement of the RCP, BTA et al. as to the serious harm they cause through many misleading statements, eg **"*the British Thyroid Association recommend the use of sensitive and specific blood tests as the only method for the precise diagnosis of thyroid dysfunction and for the monitoring of treatment with***

***approved medications*" — SOURCE: http://www.british-thyroid-association.org/news/Docs/thyroid_statement.pdf** and **"*Overwhelming evidence supports the use of Thyroxine (T4) alone in the treatment of hypothyroidism. We do not recommend the prescribing of additional Tri-iodothyronine (T3) in any presently available formulation, including Armour thyroid, as it is inconsistent with normal physiology, has not been scientifically proven to be of any benefit to patients, and may be harmful."* — SOURCE: http://www.british-thyroid-association.org/news/Docs/hypothyroidism_statement.pdf** .

To date, the BTA have **NOT** produced any "overwhelming evidence" – their statements are merely opinion. Their 'opinion' is harming patients.

The above statements are scientifically incorrect, yet they refuse to accept available medical evidence or to amend their 'guidance' when presented with references to relevant scientific studies. TPA, in refuting their claims, has adduced hundreds of references to which their attention has been drawn, to no avail.

The President of the Royal College has asserted that the RCP will not be entering into further correspondence regarding this matter. For the 250,000 sufferers who are being left without a proper diagnosis and correct treatment, this is an appalling statement.

Doctors are afraid to go against such 'guidance' as they rightly fear being arraigned before the GMC so refuse to prescribe any form of T3, even though this is indicated for specific patients. Instead, as a consequence, they are prescribing many and varied prescriptions for the various on-going symptoms, including SSRI's and antidepressants.

Whilst taking into account the costs of these medications, consideration must also be given to the massive cost to the NHS and also, the cost of other medicines prescribed when T4 alone does not fully resolve the patients' symptoms.

Many patients end up on antidepressants. Many sufferers have confirmed this to be the case. Irving Kirsch's 2008 study is the first to examine both published and unpublished evidence of the effectiveness of SSRIs, which account for 16 million NHS prescriptions a year. The largest study of its kind concluded that antidepressant drugs do not work. **More than £291 million was spent on antidepressants in 2006, including nearly £120 million on SSRIs.** Depression, anxiety, memory loss and Alzheimer's disease all have an association with lower thyroid hormone levels and research has shown that improvement can be achieved with thyroid hormone replacement.

Further, those suffering the symptoms of hypothyroidism chronically use more prescription drugs, especially for diabetes, cardiovascular disease, and gastrointestinal conditions, adding further financial strain on the NHS and an overwhelming burden to the quality of life of the 250,000 citizens who are not being given the thyroid hormone replacement they need.

How the idea could be implemented:

If sufferers were diagnosed and treated correctly, under a properly revised protocol for the diagnosis and treatment, considerable financial savings would accrue to the Health Service. However, the authors of such a guideline should be drawn from.

Patients diagnosed with hypothyroidism are given free prescriptions for life, whether their symptoms are connected with hypothyroidism or not. This should be abolished leaving free prescriptions for thyroid hormone replacement(s) only.

If doctors were allowed to prescribe T3 containing drugs for those with peripheral thyroid hormone deficiencies, they would not require other prescriptions for their remaining symptoms. Many diagnosed claim many drugs by free prescription, which may, or may not be relevant to their thyroid problem.

Two other very serious problems are the two completely physiologically different definitions of 'hypothyroidism' given by the BTA and the RCP which cause concern and confusion.

- The RCP (London) defines 'hypothyroidism as "***the clinical consequences of insufficient secretion by the thyroid gland***" - meaning 'hypothyroidism' is ONLY associated with the THYROID GLAND. This definition is the correct and narrow definition.

- The BTA define hypothyroidism as "*the* ***clinical consequences of insufficient levels of thyroid hormones in the body***". This 'broad' definition is associated with peripheral metabolism and peripheral cellular hormone reception, which produces insufficient thyroid hormones **in the body.**

If the first definition is correctly called "hypothyroidism", this should be treated with levothyroxine. Therefore, the second definition should **not** be called 'hypothyroidism'. This should be defined as 'Clinical Euthyroidism', 'Type 2 Hypothyroidism' or 'Euthyroid Hypometabolism' - and peripheral thyroid hormone deficiencies would be treated with T3 and NOT T4.

It does appear, that to avoid suggesting that T3 is needed, the diagnostics recommended for the symptoms of hypothyroidism focus **only** on the thyroid gland. When these symptoms continue, because they are caused elsewhere, i.e. peripheral thyroid hormone deficiencies at cellular level, they are not treated. Instead, if a patient continues to complain of symptoms, s/he is given the bogus excuse of “you are suffering from a functional somatoform disorder”, “your symptoms are non-specific” or “its old age”.

The result of these continuing symptoms is a reduction in the patient's ability to function, or to resist the dangerous consequences of low thyroid.

Last year, Anne Milton MP asked a question in the House on behalf of TPA in order to obtain clarification of the correct definition of hypothyroidism, but the response from Ann Keen, MP was not satisfactory. This matter MUST be resolved.

We have made repeated approaches to the DoH over the past six years, but these have been systematically ignored.

The diagnostic and treatment protocol for those suffering the symptoms of hypothyroidism must be thoroughly investigated without delay. The confusion in the definition is one of the main causes for over 250,000 patients being improperly diagnosed and improperly treated. If this issue were fixed, the NHS would save millions of pounds.

TPA is unable to progress our campaign for a better diagnostic and treatment protocol in this matter, because of the intransigent opposition from the RCP and the BTA to any suggestion that they should change their policy stance in their Guidance on the Diagnosis and Management of Primary Hypothyroidism, in the face of a great deal of scientific evidence adduced to support this demand for change.

In short, the RCP, as a setter of medical standards to improve medical practice through self-regulation, are "above the law" and a 'closed shop'. Their standards and quality are seen as implicit rather than explicit, with government and society trusting them to protect the public, and granting the profession considerable autonomy in the process.

A Public Enquiry is called for to put an end to this appalling situation.