

TPA-UK FIRST QUARTERLY NEWSLETTER UPDATE ON OUR CAMPAIGNS ETC. 21st JUNE 2008

The following is the first TPA-UK Newsletter, which I hope we will be able to send you each quarter to keep you up to date with the campaigning work that Thyroid Patient Advocacy-UK is involved in, as we are sure you would like to be kept fully in the picture. There is quite a lot to get through, so make yourself comfortable and enjoy. I hope the information is useful to you, and would like any feedback you may wish to give us.

New Members

New members, who, when first registering to join Thyroid Patient Advocacy-UK, opted to receive messages by 'Individual Emails' may, no doubt, be already regretting that decision. This forum has, at times, an enormous amount of traffic, and your Inbox is probably bursting at the seams. For the month of April alone, we received over 2300 messages. If you would rather receive a Daily Digest (meaning you can get up to 25 messages in ONE Email, or you would rather read and write direct from the website only) then please go to the Home Page of the forum website <http://health.groups.yahoo.com/thyroidpatientadvocacy> and you will see just above the broad bar at the top of the Home Page, the words "Edit my Membership". On the window that opens, click the bullet point of how you would like to receive messages. Don't forget to click "Save this Change". This should save those of you who do not want to receive Individual messages a great deal of frustration. If you have Outlook Express, if you wish, you can create a separate folder within your inbox and get all the messages from TPA to automatically go into that folder, then you need go to that folder as and when you wish. The instructions on how to do this are in the FILES in our forum website.

TPA-UK Responses to the BTA Statements on synthetic T4/T3 combination therapy and natural thyroid extract (Armour Thyroid)

The British Thyroid Association's Executive Committee produced two statements on synthetic T4/T3 combination therapy and Armour Thyroid and published these on their website. TPA-UK found many of their statements were misleading, and in parts, incorrect. They backed up the whole of these statements with 4 references. TPA-UK have responded to both their statements and asked the Executive Committee of the BTA to update them with the correct information. Our responses were sent to BTA on 17th March 2008. To date (3 months later), they have not even acknowledged receipt. These responses were also sent to all NHS endocrinologist and all PCT's as they are responsible for the funding of Armour, should a doctor be happy to prescribe it. It is quite appalling that endocrinologists are copying both the misleading and incorrect information in the BTA statements and handing them to their patients who ask for a trial of T4/T3 combination therapy or Armour Thyroid, telling their patients "...this is the reason why I will not recommend synthetic combination therapy or Armour..."

The British Thyroid Foundation have a similar statement about T4/T3 combination therapy and Armour Thyroid on their own website. I received a letter from them acknowledging receipt of our responses, telling me this will be discussed at their next meeting of their Trustees some time in June. We await their decision. Meanwhile, you can read these responses with almost 300 citations to back up our evidence, and, if necessary, print them off to show your GP or endocrinologist http://www.tpa-uk.org.uk/resp_bta_armour.pdf and http://www.tpa-uk.org.uk/resp_bta_t4t3.pdf

Goldshield Pharmaceuticals Patient Survey (Levothyroxine)

Goldshield Pharmaceuticals, one of the manufacturers of levothyroxine tablets have contacted TPA-UK to say they are currently addressing some of the issues faced by patients

taking levothyroxine products. They have asked if members of TPA-UK would participate in a short survey? The aim of the questionnaire is to understand if there is a need to improve existing thyroxine therapies and whether there are unmet needs to either modify existing or developing new presentations. Please take part http://www.tpa-uk.org.uk/goldshield_survey.php

Armour Thyroid Shortage - BE PREPARED!

Many of you who are taking the thyroid hormone replacement Armour Thyroid, which is manufactured by Forest Laboratories will no doubt be aware that there is a serious supply problems at present and is likely to continue until end of September/early October 2008. This is worrying, because originally, we were told the supply problem would be sorted end of January/February, and then end of May/June and now end of September/October. We have no guaranteed...

I heard from Afshin on 17th June at www.internationalpharmacy.com who assured me that Armour is definitely NOT going off the market. He told me that Forest is currently changing the manufacturing process of the product and they are calling it 'an enhancing procedure' (you may have noticed that the new batches no longer have a distinctive odour). He told me that 1 grain and lower is now available and that the 1.5 grains will be available after the 9th of July and the higher strengths are flagged for distribution end of September or early October. It is a little concerning that we are not being told what the "manufacturing process change" is, nor why it had been necessary to do this. He told me that he is at the mercy of the manufacturer on the above dates and that he is as frustrated as our members about this matter, and that it has greatly affected the service he can provide.

He tells me that RLC Labs is another company that markets Nature-Throid. Their product has the same active ingredients as Armour Thyroid and if you are unable to get the dosage of armour you need, you can purchase this. He assured me it is just a different brand. You will note there is also a generic version of Armour available from International Pharmacy that is marketed by Major Pharmaceuticals.

Whatever the true cause of the lack of production on the higher doses of Armour, we are now suffering from a worldwide shortage.

In the meantime, please do not become too concerned about this. If you get your Armour via NHS prescription (as I do) and your pharmacist is unable to supply your Armour, do NOT be persuaded by your GP to go back onto Levothyroxine. You went on to Armour because the synthetic thyroxine did not make you well, and you do not want to go back to the place you were in before Armour. You can continue to take natural thyroid extract, but it will mean you will have to switch to another brand name, or even use a generic.

First, please be assured that I have today spoken with a member of staff at IDIS World Medicines who source Armour Thyroid for your Pharmacist. They assure me that they do have supplies of Nature-Throid and all your doctor has to do, is to write 'Nature-Throid' (for the treatment of hypothyroidism) on your prescription form instead of 'Armour' and your prescription will be fulfilled in the usual way. Before you do this however, please contact your local pharmacy that supply your Armour thyroid and ask them if they have any left in stock that might cover your prescription for the next three months. All dosage sizes of Nature-Throid are fully stocked at the moment. The only difference between Nature-Throid and Armour Thyroid is that Nature-Throid is hypoallergenic, for those sensitive to some fillers or binders.

You may need to talk to your GP about this problem and ask him to write on your usual prescription form that if Armour is unavailable, to substitute with the Western Research products Nature-Throid is acceptable and IDIS is aware of this. You will get a straight 'swap' temporarily from Armour to Nature-Throid. If there is any difficulty with this – IDIS World Medicines should sort this out.

It is imperative that you get your future NHS prescriptions sorted with your doctor and pharmacist, because the shortages of Armour could get much worse before the end of September/beginning October (if, indeed, these dates are met)

For those of you who purchase your own supply of Armour from an Internet Pharmacy, I would recommend that if you are unable to get the size of grain that you require, you be guided by www.internationalpharmacy.com in their recommendations to switch temporarily to Nature-Throid or to Major Thyroid.

Publication of TPA-UK Hypothyroid Patient Survey

We are delighted to announce that the TPA-UK Hypothyroid Patient Survey has now been published on our website www.tpa-uk.org.uk. We would like to thank everybody who contributed towards its creation and to those who helped in its completion. I would especially like to thank those of you who have been so patient in waiting for the publication of these results during the processing of the raw material.

The idea for TPA-UK to compile a Survey originated from the Medical Advisory Service (MAS) to whom we are grateful. They also drew up a 'plan of action' and provided the contact details for NSM Research. Members of the TPA-UK Forum created all of the questions in the survey and Dr Barry Durrant-Peatfield (Patron and Medical Adviser to TPA-UK) peer reviewed the final results.

All members agreed the final version before it was passed to NSM Research (Market Researches) for analysis and presentation. They then drew up and printed the questionnaire for distribution. I applied for an award, specifically to meet the costs of the survey, and was awarded a grant of £4900 from UnLtd Millennium Awards. UnLtd told me my award could be used for any other thyroid campaigning project or to disseminate other information if I needed to do this. I chose to fund the cost of the survey through this award as I had originally applied to do.

The entire ethos of patient support forums is that they are run predominantly by volunteers who give of their time and expertise freely and often, anonymously where that is permitted - so thank you to all who took part in its creation and its completion. Time and online costs were 'volunteered', contacts were volunteered, personal 'credibility' was volunteered, support was volunteered; the entire phenomenon is an acknowledged success story. This survey was created 'in common' for a 'common good'. However, although I know all the contributors to the survey would not wish to be named, we would like to thank Dawn Wood (previous member of TPA-UK) for volunteering to compile and edit the questions sent to the forum and for drafting the covering letter on behalf of TPA-UK. We also thank Louise Hartup, who spent weeks of her time freely going through the raw results to help simplify them, by translating them into graph form for the final version.

In this survey of 1500 hypothyroid participants, which was undertaken in 2005-6, the dissatisfaction of many patients is highlighted. Of all respondents, 93.8% (n=1407) had not been told of medicines other than L-thyroxine by their medical practitioner. 38.8% (n=768) felt they had "not been dealt with very well" or "not very well at all" by their doctor whilst seeking a diagnosis of their symptoms; 233 (15.5%) had given up paid employment; 300 (20%) had taken time off work as a result of thyroid illness; 500 (33.3%) felt their close relationships had been affected by thyroid illness and 632 (42.1%) had stopped or altered their exercise routines as a result of their symptoms. What specifically stood out is the question asked of those sufferers on levothyroxine therapy alone, when asked the question, "do you feel you have fully regained your optimal state of health?" 1176 (78.4%) Answered "No".

These results have been passed to Dr Colin Dayan (Head of Medical Research, Bristol University), before it went for publication. He was highly complimentary on the work by TPA-UK members and the huge effort that had clearly gone into the reports creation.

At a further meeting in Bristol towards the end of March 2008 with Bob, Dr Colin Dayan and Dr Vijay Panicker, the TPA-UK Survey was run through on screen, the information being matched to the information they had already assembled from their own work. In looking at the various results, what stands out is the amount of economic distress caused through this disease i.e. c 33% of 1500 participants had had to give up work, many being forced to live on State Benefits, or to take reduced hours. You will see that this is matched and supported by the numbers reporting extreme tiredness in the (untreated) symptoms survey, again about 33%.

By the end of the meeting, Dr Dayan summed up the points of interest to him and asked if the respondents to the survey were known. I am now in possession of all the postal results since they had been stored at NSM Research for a year and were about to be scrapped, before we suspected that there was far more information available than had been realised previously. NSM sent me all the paper questionnaires. Dr Dayan noted from the relevant chart there had been 608 postal responses, but these were 'unaccessed' for confidentiality, and we only had the postcodes for participants. There were 892 online responses. It is clear that Dr Dayan has taken on board the economic distress aspect of the Survey, well illustrated by the other economic data supplied by the detail in the long questionnaire.

Exciting New Research - We need your Involvement!

In a very recent study (May 2008) headed by Dr Vijay Panicker it has become clear why there are problems with the much 'revered' TSH test. This study showed that a common variation in the deiodinase 1 gene D101 is associated with the relative levels of free thyroxine (FT4) and triiodothyronine (T3). This study provides the most convincing example of common DNA variation that alters circulating thyroid hormone ratios in the general population. This variant may be useful in dissecting causal relationships between thyroid hormone levels and related traits in different tissues <http://jcem.endojournals.org/cgi/content/abstract/jc.2008-0397v1>. It is the polymorphism (SNP) that controls the effectiveness of the DIO(1) deiodinase type 1 - it affects the ratio of T3/T4 and also, the TSH doesn't vary under this control mechanism. DIO(1) therefore controls what happens in the tissues and this might help explain the 'apparent' variability of response in hypothyroid patients treated with Levothyroxine only. Note the 1176 (78.4%) respondents who answered "No" when asked if they had regained their optimal health on T4 therapy alone in the hypothyroid patient survey.

As a rough estimate, if there is one DNA polymorphism that confers a biological advantage/disadvantage one might expect it to affect about 25% of the sample (homogeneous carriers) and the other 25% not carrying it, should be affected in the opposite direction (i.e. disadvantage/advantage). In between, the heterogeneous carriers might comprise about 50% of the population. So – if one saw a sample more or less disadvantaged at about the 75% level (i.e. 50 + 25%) – and the remaining 25% relatively, it would, perhaps, indicate that a genetic polymorphism was at work, hence the interest that 78.4% of respondents in the survey said that they had not returned to optimal good health.

This was originally thought to comprise a heterogeneous self-selected sample (it was in the first place, but the surprising numbers that came out of the survey seem to point in one direction. If a sufficiently large prospective study shows that the SNP found in the study by Panicker et al, it is the one that affects the estimated 75% of the so-say heterogeneous sample that is a very strong candidate as explanation for the disparity in response to levothyroxine on its own.

To further this study, Dr Dayan wants to see if the same polymorphism is affecting all the non-responders, i.e. do they form a homogeneous group? Should he gain ethical approval, he would like to contact more sufferers of hypothyroidism, for the purpose of obtaining a biological sample (blood) to enable a DNA profile to be obtained. He said it would take a while to talk to some of his epidemiological colleagues, and we assume this would be to establish the criteria necessary to submit a proposal for further research. What they are keen to look at is this relatively new technique of seeking 'Single Nucleotide Polymorphisms (SNPs)' within the genome of each individual sampled to establish if there are any correlated SNPs that recur in the genome of patients who *don't* respond well to levothyroxine therapy as strongly

indicated in the paper above. TPA-UK has, arbitrarily, found a 'self-selected group' of patients that matches a criterion useful in establishing the truth of the matter, - i.e. why do some patients not get well quickly and reliably. Note the 78.4% who answered "No" when asked if they had regained their optimal health on T4 therapy alone.

If you would like to be part of this further research and you would be willing to give a sample of your blood (I understand this would be taken by your GP), would you please let me know, giving your consent to be included in this study, your full name, home address and telephone number, so I can pass these to Dr Dayan or one of the members of his team so they can contact you.

NHS Patient Opinion - Good or Bad

Please don't forget that you now have a chance to tell the NHS your story, good or bad, about your experience within the NHS. The staff running the 'Patient's Opinions' website are already publishing our stories and not editing them in any way, so this appears to be one way to get the truth out about our desperate plight. Please do not miss this opportunity, as we don't often get the chance to tell the NHS what we really feel about their diagnostic and lack of treatment choice - again, good or bad. www.patientopinion.org.uk

TPA-UK Need Your Thyroid Story - Good or Bad

Please also, if you have not done so already, write out your 'story' if you would like it to be included in a project that is on going. I am collecting as much information as I can about many aspects of hypothyroid disease within the NHS and it is vital that I have patient's stories about the suffering they have been put through to back up other evidence, before finally getting a diagnosis, or the problems they have had with the NHS treatment protocol of using Levothyroxine only therapy. You can send your story to me at info@tpa-uk.org.uk

Does your local Primary Care Trust Fund ArmourThyroid?

Lilian is contacting her local Primary Care Trust (PCT) as she is having a "battle" about the prescribing of synthetic Liothyronine (T3) with her Primary Care Trust. She does not want to know the name of individual doctors who prescribe synthetic Liothyronine (T3) or natural thyroid extract Armour Thyroid, but if you are lucky enough to be prescribed either within the NHS, please would you let Lilian know the name of your PCT so she can make a list of all of these. For anybody needing the full address and details of their Primary Care Trust in the UK you can find them here <http://www.nhs.uk/servicedirectories/Pages/PrimaryCareTrustListing.aspx> Please email Lilian directly at lilian15@ntlworld.com

Dr Peatfield's Metabolic Clinic venues and dates

Dr Peatfield is holding another of his Metabolic Clinics at my cottage on 19th and 20th July. If you would like an appointment, please contact me as a matter of urgency sheilaturner@tpa-uk.org.uk . I live on the Pennine Way between Skipton and Keighley, yet only 3 miles from the Lancashire border. You can see Dr Peatfield's other metabolic clinics throughout the UK at www.tpa-uk.org.uk

Sheila and Lee
www.tpa-uk.org.uk