

THYROID PATIENT ADVOCACY-UK

NEWSLETTER NO. 2

DECEMBER 2008



The following is the second Thyroid Patient Advocacy-UK Newsletter, which I hope we will be able to send you whenever we have enough information to keep you up to date with the campaigning work that TPA-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 get comfortable and enjoy. I hope the information is useful to you, and would like any feedback you may wish to give us.

For all New Members

If you opted to receive messages by 'Individual Emails', you may, no doubt, be already regretting that decision. This forum has an enormous amount of traffic, and your Inbox is probably bursting at the seams. For the month of April alone, we received over 2600 messages. So 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) go to the Home Page of the forum website: <http://health.groups.yahoo.com/thyroidpatientadvocacy> and you will see just above the broad dark green bar at the top of the Home Page, the words "Edit my Membership".

In the window, 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.

Dr Peatfield's Metabolic Clinics

For anybody within driving distance of Yorkshire, Dr Peatfield is holding another Metabolic Clinic in Ickornshaw (Nr Skipton) on Monday 19th, Tuesday 20th and Wednesday 21st January 2008. If you would like a consultation with him at this time, please contact me at sheilaturner@tpa-uk.org.uk or telephone 01535 636014 as soon as possible. If you need overnight accommodation, we have excellent B&B in the village (around £25 pppn). Check out the venues for Dr Peatfield's other clinics. http://www.tpa-uk.org.uk/drpeatfield_clinics.php



NHS Patient Opinion - Good or Bad

Don't forget that you now have a chance to tell the NHS your story, good, bad or indifferent 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 protocol and our refusal to be given a choice of treatment - 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' and send it to me 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



I would like stories also from members who were so ill, refused a diagnosis because their blood results were 'normal' and who eventually were forced to leave the NHS to seek a private consultation and/or who had to self diagnose and self treat use natural thyroid hormone replacement and managed to get their full health back.

TPA-UK Yorkshire Get-Together 2009

I am hoping to once again host our TPA-UK Annual Get-Together (sometime in April/May 2009) at my home at Squirrel Cottage and will once again be arranging our lunch and afternoon venue at Alfe's Restaurant in Keighley – which everybody agreed was absolutely excellent with wonderful service and delicious Thai and Chinese Food. This lunch is a set buffet and costs about £7.00 per person. For those of you who have never attended, I can assure you that this is not to be missed. You can have a look at some of the photo's that were taken last April (These are in the Photo's section of our Forum website). You can also check out Alfe's restaurant

<http://www.alfes.co.uk> where you can click on 'Menu's' and 'Gallery'.

Once again, Dr Peatfield, Dr Skinner, Dr Achmed are hoping to attend and this time, Afshin (the owner of International Pharmacy in the US) will also be coming over specifically to meet us all. As soon as we have set a date, I will let you all know, and as this is a very popular function, I would advise getting booked up early, especially if you need overnight accommodation in the village.

Complaint on the Unfair Trading Practices of Endocrinology and Its Guidance of Practitioners.

As well as the above Complaint prepared by Eric and myself, which is now in the hands of Investigators of the Trading Standards Office, we have now prepared a 60 page Human Rights complaint on the Practices of Endocrinology and Its Guidance of Practitioners regarding certain ignored maladies for which government approved medications are available but denied. As soon as we

have further information regarding both of these complaints, we will let you know. Because the content at this time is confidential, we cannot publish these yet.

Please sign our Medical Justice Petition to help back our complaint to the Office of Fair Trading and other organisations

Will you also sign this very important petition

<http://www.petitiononline.com/tpauk123/petition.html> for Medical Justice to help back the TPA-UK Official Complaint on the Unfair Trading Practices of Endocrinology and ITS guidance of Practitioners. Copies have been sent to the European Commission and the Chairman of the Government's Public Accounts Committee. If you are a member of other thyroid online community forum groups or if you own a thyroid-related web site, emailing this petition announcement to your members, colleagues, family and friends in order to gather more signatures would help us all.

Also sign the International Patient petition

This petition has been compiled by patients for patients. It will eventually be used to lobby medical boards throughout the world in the hope they will change their treatment protocol for hypothyroidism and allow all patients a choice of treatment. http://www.tpa-uk.org.uk/international_patientpetition.php

Please let as many people as possible know about this petition. We need as many signatures as possible in order to lobby medical boards throughout the world.

TPA-UK Information pack

For the past 4 years, TPA-UK has developed a 56-page Information Pack that provides comprehensive information on all aspects of hypo - thyroidism, including the symptoms, signs, diagnosis, tests and treatment of hypothyroidism. If you have members of your family or friends who are suffering the symptoms and who do not have access to the Internet, this Pack can be ordered by downloading and printing out the information pack order form http://www.tpa-uk.org.uk/info_pack.php. Please fill out the form and enclose your cheque for £7.00 OR, you can now also order the TPA-UK Information Pack online. Simply [send us an email containing your request](#), along with your name and postal details. Then, log into your PayPal account (or register with PayPal to make online payments and send/receive money) and send your payment for £7.00 to: sheilaturner@tpa-uk.org.uk





The Thyroid Patient Advocacy-UK Response to “A Statement from the British Thyroid Association Executive Committee on Armour Thyroid” and “ A statement on the use of combination thyroxine/triiodothyronine(Liothyronine) therapy”

TPA-UK disagrees with many of the statements made by the Executive Committee of the British Thyroid Association (BTA) on natural desiccated porcine thyroid extract (Armour® Thyroid, USP) and on the Use of Combination Thyroxine/Triiodothyronine (Liothyronine) Therapy. TPA-UK are very concerned that the BTA continue to advise that L-thyroxine (T4)-replacement remains the treatment of choice despite the amount of evidence contrary to their opinion, showing it to be ineffective in relieving many patients' symptoms. This research paper extensively refutes the incorrect and inaccurate BTA statements on Armour Thyroid. You can read our responses to the BTA Executive Committee that were posted to them on 19th March 2008. To date, neither the BTA or the BTF have acknowledged receipt of the TPA-UK rebuttals, nor have they amended their statements with the correct information. Please show these responses to your doctor if they follow the BTA's recommendations and if they refuse to give you a trial of either synthetic combination T4/T3, T3 alone or Armour Thyroid.

Warning: The BTA statements included in both papers deal with hypothyroidism as deficient thyroid secretion only. It has no bearing on deficient post-thyroid operations upon thyroid hormones.

http://www.tpa-uk.org.uk/tpa_responds1.php and

http://www.tpa-uk.org.uk/resp_bta_t4t3.pdf

Your chance to help support Thyroid Patient Advocacy-UK

You can now support TPA-UK by purchasing **ANY goods** from Amazon UK! Simply click on the image below. This will take you directly to Amazon UK where you can purchase anything those listed on our website, copy the title and paste it into the search window on Amazon UK.





**We are delighted to announce that
in August 2008, Thyroid Patient
Advocacy-UK was accepted into
PATIENT ADVICE AND LIAISON
SERVICES (PALS)**



Free prescriptions for sufferers of hypothyroidism

If your doctor has not told you, please be aware that once you have been diagnosed with hypothyroidism, you are entitled to receive all of your prescriptions free of charge. This means any prescription, not just those for thyroid hormone replacement. In addition, anyone needing regular prescriptions (other than thyroid) may save money by buying a Prescription Prepayment Certificate. This article highlights who is entitled to receive free prescriptions, as well as lists the medical conditions that qualify for an exemption certificate.

An update on the situation regarding Armour Thyroid, USP

Many of you will still be very confused and concerned at the situation regarding the production of the larger grains of Armour Thyroid. As you are aware, we keep being given different dates when the larger grain tablets will be available, but time and time again, this date is bypassed and we are again given another date, usually in another three months. The latest date we had been given was the end of October 2008 – but then Forest Pharmaceuticals extended this to the end of the year. We have now been told that the larger grains will probably not be available until the beginning of next year. As this has been going on for almost a year, we decided to find out exactly what the problem was/is, as we have been told many different versions and never the truth.

We have been in close touch with the manufacturers (Forest) and with Afshin (supplier) of International Pharmacy. We have also been in correspondence with RLC Laboratories and the manufacturers of Nature-Throid and from what we have gathered, the following seems to be the present situation. We have received the following information from no other source other than Forest, International Pharmacy, RLC Labs. and BR Pharma.

I asked Afshin outright if there was a problem with a shortage of raw material. Forest and RLC have now confirmed that one of the problems they were experiencing previously was such a shortage, but that this is no longer the case. However, it would appear that Forest are having a difficult time getting the higher strengths of thyroid pills to fall into the specification required by the



USP and this is the reason why they keep on delaying the release date – so this has been ongoing for some time. Forest has promised us yet again, that they will have the higher strengths by the end of this month (December). RLC have told us they are not expecting any until next year – and they didn't even say the beginning, the middle or the end of the year

We have learned that the manufacturing procedure has completely changed and the new pills no longer have the distinctive smell that they used to have, as many of you will have noticed from the small grains of Armour. I asked Afshin how the manufacturing procedure had changed, but he told me he is not sure, but he said that ALL of the present problems with supply started after the change in removing the smell. We have tried to find out what initiated the change in the manufacturing procedure, but Forest is saying nothing. Forest, it appears, is just another big drug company after people's money and showing it cares nothing about its consumers. They have done nothing whatsoever to put our minds at rest.

We have also been in contact with the manufacturers of Nature-Throid (BR Pharma) who use the same thyroid powder for their tablets as used in the tablets Armour and Westroid. The representative from BR Pharma told us that he is in direct contact with RLC all the time and they have assured him that their product (Nature Throid) will not be discontinued at all. However, he tells us that he has heard rumours that Forest is planning to discontinue its Armour brand due to some FDA pressure. He says he is not sure of the reason why, but from what Afshin has told me, I believe there is a possibility that this could be more than just a rumour and I thought it fair that we should give everybody a timely warning so you can prepare for the future. I hope this is a rumour, but we cannot go on for very much longer without having a plan of action in place in case we suddenly find there is no more Armour available.



I can confirm the FDA has approved Nature-Throid. Any FDA approved medicine is assigned an NDC number (which is printed on the pack). It is usually the barcode number. We have been assured that each time BR Pharma import Nature Throid, they have to ask the Medicines and Health Care Products Regulatory Agency (MHRA) for permission (in writing) and provide exact details of the product and source. The representative from BR Pharma has categorically stated that MHRA has allowed them permission to import. BR Pharma keeps their written Approvals on file. They go through a strict screening process to make sure what is being imported is licensed and necessary for UK patients. I



would recommend you keep this information safe in case we do, eventually, have to find another desiccated porcine thyroid products to replace Armour. It is better to be safe than sorry. I have written to the MHRA in the same way I did in 2004 when I asked if Armour Thyroid could be prescribed by NHS

Stop the Press

I have today heard from MHRA who state that they CAN confirm that the situation as stated in their original letter to me in 2004 about the prescribing of Armour also applies to Nature Throid and Westhroid but please note that where the letter states "We have not told importers that they must provide evidence from prescribers, as this is a matter of clinical judgement" that they do reserve the right to request this information should they deem it necessary. They do not normally object to importation of the products I named. However please note that even though a prescriber may be able to prescribe anything they wish, this does not mean that it can necessarily be obtained - especially if the MHRA were to object to importation of an imported unlicensed medicine. So, it is official that both Nature Throid and Westhroid can be prescribed within the NHS in the same way as Armour thyroid.

doctors if their patients were not doing well on the synthetic thyroxine alone, and their response is in our FILES. I have again, asked them to write to me formally to set out the details regarding the switch from Armour to either **Nature Throid** or **Westhroid**. I anticipate no problems with this whatsoever; it is just a question of getting everything straight and above board.

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 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-Thyroid and have told me that all your doctor has to do is to write "Nature-Thyroid (for the treatment of hypothyroidism)" and the dosage required 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 supplies your Armour Thyroid and ask them if they have sufficient stock left to 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 so you might even do better on this product.



If you get Armour via NHS prescription, it might be an idea to talk to your GP about this problem and ask him to note on your usual prescription form that if Armour becomes unavailable, to substitute with the **Western Research products Nature-Throid or Westhroid** as this is acceptable and IDIS is already aware of this. You should get a straight 'swap' from Armour to Nature-Throid or Westhroid. If there is any difficulty with this – IDIS World Medicines should sort this out.

Some of our members have already swapped from Armour to Nature Throid or Westhroid (Dr Peatfield swapped some time ago and has not noticed any difference between Armour and Nature-Throid. If you do experience any problems, or your GP is concerned, Amandip, the representative from Nature-Throid is a very helpful guy and he says that should it become necessary, he is willing to talk to anybody's GP, and this might be useful for those members who have difficulty in convincing them that natural thyroid extract is both safe and effective.

It is imperative that you get your future NHS prescriptions sorted with your doctor and pharmacist as soon as possible, because the shortages of Armour could (and I sincerely hope it doesn't) get much worse before the end of the year or next year, if, indeed, these dates are met. I need to notify you about this problem as a matter of some urgency because I understand that InHousePharmacy has already run completely out of all grains of Armour – they have none left whatsoever.

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-Thyroid /Westhroid or Major Thyroid.

The latest news about Prednisolone

Afshin, the owner of International Pharmacy has written to me today and is very sorry to report that Prednisolone is no longer available under its generic name in the US. The same product from the same manufacturer is now being marketed under the brand name MILLIPRED – unfortunately, at a higher price.



A message from Eric for those of you with hypothyroid symptoms, but not getting a proper diagnosis or treatment.

You go to your doctor because you are suffering many of the non-specific symptoms of hypothyroidism. Your doctor tests your blood to check your thyroid function. The results all come back within the normal reference interval and s/he doctor tells you that you do not have a problem with your thyroid. Quite often, your doctor will try to persuade you that you are depressed and prescribe antidepressant drugs and/or s/he will tell you to take more exercise, change your diet and come back for another blood test in 6 months or a years' time. You are sent away to get on with your life, because medical practice has stopped at this point and ignored completely, and if you carry on complaining about your symptoms, s/he declare that you suffering from a "functional somatoform disorder." In other words, it's all in your head...

So why are doctors refusing to give you the medical care you deserve and looking for the cause of your symptoms if they believe your normal thyroid function tests mean that you are 'normal'? You can see this in a comparison of the medical practice guidelines for hypothyroidism and those for hypothermia. The hypothermia guidelines are filled with possibilities as to the cause e.g. deficient hormones, exposure, adverse reactions to drugs, etc. However, the hypothyroidism guidelines point to the thyroid gland only, and they do not mention any other possible cause for your many symptoms. Neither do these guidelines mention the potential for post thyroid deficiencies or the potential deficiencies in other hormones.

A second, substantial component, of the problem is the imprecision in the language. This imprecision gives medicine a "cover" for its systematic malpractice. The term "hypothyroidism" has both a proper narrow meaning and an improper broad meaning. The proper narrow meaning is deficient secretion of thyroid hormone by the thyroid gland. The improper broad meaning is deficient levels of thyroid hormone in the blood. This is complicated by another linguistic imprecision, "thyroid hormone." Although thyroxine (T4) is produced only by the thyroid, Triiodothyronine (T3) is produced mainly by conversion sites located within a variety of organs around the body, hence the name peripheral conversion. So although the liver produces 60% of the T3, it is not a liver hormone but a thyroid hormone.

So what happens when your thyroid function is tested as "normal" but you still have the symptoms of hypothyroidism? Your doctor, dedicated to the existing paradigm, will give you the diagnosis of "functional





somatoform disorder" because you have (in medical narrow vision) no detectable problem. The ethical practitioner, who knows medical science, will know that the thyroid function tests (TSH, Free T4, and antibodies) test the thyroid gland and provide some inferences upon preceding deficiencies. S/he will know that the regulatory capability of the peripheral conversion (or metabolism) will isolate the T3 levels from the T4 levels to some degree, and consequently and consequently the thyroid tests do not indicate what is happening post thyroid or after the thyroid. The ethical doctor will then attempt, at his/her peril, a trial of a T3-containing hormone replacement.

There are two post thyroid operations, the peripheral conversion of the mainly inactive hormone T4 to the active hormone T3 and subsequently the reception of the T3 by the body's cells by hormone receivers so that it can be used by the cells' nuclei. And then there is the actual use of the T3 by the nuclei. All of the operations are made possible by various enzymes...

Please note that since all of these hormones are delivered in the blood stream, these hormone receivers are physically structured to accept only their hormone by a physical size and shape match. It is rather like standing about a luggage conveyer at an airport looking for your luggage. You let bags that are not yours pass, but when you see yours, you grab it. So there are hormone receptors everywhere. But behaviour of the hormone receptors in the thyroid gland for Thyroid Stimulating Hormone (TSH) cannot be distinguished from gland production issues readily -- and it hardly matters. But hormone reception in the body's cells is another matter.

Now, let's revisit the tests. Medical practice does not prescribe any tests for the post thyroid realm. Consequently, they know nothing of it, so deficiencies in this realm go completely unnoticed by the tests. But some explanation is needed for you, the patient -- so what do they do -they do what medicine has always done - put the blame somewhere else and you, the patient will do. Your doctor will tell you that the suffering is all in your mind -- "functional somatoform disorder" or "non-specific symptoms."

However, medical science has known of post thyroid operations upon T4 and the importance of T3 for nearly four decades. Nonetheless, the endocrinology establishment ignores or dismisses this medical science.

But, there ARE doctors who have moved ahead. Brady postulates a reverse T3 test (rT3) to detect the body's deficient use of T3, since rT3 is made if there is plenty of T3 in the blood or if conditions are not favourable for making T3. Baisier -- et al. prefers the level of T3 in a 24 - hour urine sample and also postulates a clinical test upon a combination of eight of the "non-specific symptoms."





Further, there are approved and accepted T3 containing hormone replacements. But when incomplete testing is deemed the gold standard, prescribing these replacements is tantamount to medical heresy. Unfortunately, the medical heresy has been and is continuing to be committed by the medical establishment in its dismissal and ignoring of medical science.

It really all boils down to the following simple concept chain:

1. Medical science declares and proves that there are operations on the thyroid hormone T4 to produce the active hormone T3 and to receive the T3 for use in the body's cells' nuclei.
2. The medical establishment believes that all bodily functions can become deficient and/or fail.
3. Evidence Based Medicine (EBM) requires the investigation of all possible causes known to medical science for the patient's symptoms before finalising upon a diagnosis and therapy.
4. But medical practice does not follow EBM in this niche of medicine. It ignores the existing medical science of the post thyroid operations upon T4 and T3. Consequently, it cannot rationalise the prescription of any T3 containing hormone replacement. And then to provide a diagnosis, it improperly and unprofessionally uses imprecise language, makes over broad conclusions, and offers the "functional somatoform disorder" blame upon you, the patient. Not only does medical practice not care for the patient, it blames its own frailty upon the patient -- a double whammy.
5. So people with deficient post thyroid operations are doomed to suffer unless they are fortunate enough to find a physician whose ethics overcome his fear of the General Medical Council and their punishment powers for committing the medical heresy of properly treating their patients.

Once again, I wish to raise your determination to correct this problem. You can rest assured that Sheila and I are doing what we can as two individuals to correct this problem. But unless, we can find powerful sympathetic ears attached to minds set against the systematic abuse of the people, we will need help in changing those minds.

Writing to your Member of Parliament is a beginning, not only will you be helping yourself, you will be helping all sufferers of the symptoms of hypothyroidism, so why don't you write to your MP right now... You can find your MP through typing your postcode in this link <http://www.writetothem.com/>



A VERY HAPPY

&

HEALTHY CHRISTMAS
TO EACH AND EVERY
ONE OF YOU.

LUV – SHEILA AND LEE