Thyroid Patient Advocacy

Christmas Newsletter December 2010

Thyroid Patient Advocacy - Registered as a Company Limited by Guarantee in England & Wales, No: 7222939.

Charity Number: 1138608.

Registered Office: Squirrel Cottage, Ickornshaw, Cowling, N.Yorks. BD22 0DH.

Trustees

Dr Barry Durrant-Peatfield (Patron)

Sheila Turner (Chair)

Gill Bell (Secretary)

Marie Holloway

Jenny Stenning

Mark Willoughby

INTRODUCTION

These last few weeks have seen a hive of activity in our project to get us fully registered as a Charity. As many of you are aware, TPA has been run very successfully on a completely voluntary basis since July 2007. In just under 4 years, we have seen a steady growth in membership (now standing at just under 2000). The last couple of years has also seen increased activity in the campaigning work we are involved in which has been undertaken by our team of wonderful volunteers, most of whom suffer with thyroid problems themselves, or who have a member of their family with a thyroid or related problem, and who wish to be actively involved in helping others.

The TPA team works with health professionals, service providers and the public, by promoting high standards and professional competence in the provision of patient care. This is in order to bring about the relief of sickness and preservation of the health of persons suffering from thyroid and thyroid-related diseases and conditions in the UK and worldwide. This is particularly, but not exclusively, by educating and promoting good practice, as the Trustee Directors shall determine from time to time.

TPA is actively involved in the process of setting up a number of local thyroid support groups, and is seeking to increase this network. You can read more about these groups in this Newsletter and if you would like to become involved in this project, please let us know.

Funding of research activities is a very important area for TPA, as is the funding of the necessary campaigns to help bring about a better protocol in the diagnosis and management of thyroid and thyroid related conditions. We also assist medical research by obtaining data through questionnaires and surveys distributed via our newsletters, the media and through our website to all sufferers of thyroid disease and related conditions. You will be aware of the UK Hypothyroid Patient Survey we carried out in 2005/2006 (results can be seen here http://www.tpa-uk.org.uk/tpauk_survey.pdf.) which was carried out through a grant of £5000 awarded to me from UnLtd Awards (Millennium Awards). We now need £20,000 to fund a similar European Hypothyroid Patient Survey (we already have donations just short of £12,000, so any help here with ideas or donations would be gratefully received).

We are keen to encourage membership of TPA, not only from people with a thyroid disorder, but also from amongst the medical profession. If you wish to learn more about the work of TPA, please see our web site www.tpa-uk.org.uk and/or join our Internet Thyroid Support Group. As a member of TPA you will receive our free quarterly newsletter containing articles by our medical advisers and other professionals on various aspects of thyroid and thyroid related disease, plus details of our local support groups' activities and reports of our Public Annual Conferences, which are becoming extremely popular events.

As well as becoming a member of Thyroid Patient Advocacy, we hope you may be able to help us in several ways:

- by informing others sufferers about the support we can offer them;
- by displaying our TPA poster in public areas, i.e. surgeries, hospital waiting rooms, slimming clubs, libraries, WI venues etc;
- by distributing our patient brochure (in the process of being created) and by contributing to our newsletter.

Also, our local thyroid support groups would welcome your assistance and encouragement. Please do let us know if you feel you can help in any of these ways.

There is much to be done in the way of promoting awareness of thyroid disorders, the much needed changes in the diagnosis and treatment of those with the symptoms of hypothyroidism and related conditions, helping people with thyroid and related conditions and encouraging medical research. By joining TPA we hope you would gain an insight into both the patients' perspective of their disorders and the medical practitioners' perspective.

Please support our work

In Spite Of Your Symptoms, I Am Continuing Your Levothyroxine-Only Therapy

I saw a woman wearing a sweatshirt with 'Guess' on it. I said, 'Thyroid problem?' **Arnold Schwarzenegger**

TPA 2011 CALENDARS FOR SALE

TPA is now offering for sale a choice of two beautiful calendars for 2011 and we are delighted with these. Both calendar designs create a year-long gallery of wonderful images displaying either beautiful flowers or birds in their natural habitats. Well done Kathleen Ranger, a long-standing member of TPA, who has taken the stunning photographs herself and designed the Calendars.

Each month features a new image along with informative captions taken from the Home Page of our web site www.tpa-uk.org.uk

If you feel that you have benefited from the information, help and support you have been given by the TPA web site and/or our Internet forum and would like to show your appreciation, why not buy a calendar (or two) - which will in turn, benefit others.

Proceeds will be donated to Thyroid Patient Advocacy. You can pre-order these calendars today for **£5.50** each (postage and package included) if ordering in the UK, or **$7.63** if ordering from Europe or the US. Buy one for your family and friends in time for Christmas. Please indicate whether you would like the 'Flower' or the 'Bird' calendar when ordering.

Please write cheques made payable to 'Thyroid Patient Advocacy' and send to:

Thyroid Patient Advocacy Head Office, Squirrel Cottage, Ickornshaw, Cowling, Nr Keighley, BD22 0DH, North Yorkshire, United Kingdom.

Alternatively, you can pay through Paypal *to* sheilaturner@tpa-uk.org.uk *or* you can pay direct by Bank Transfer to the TPA bank account.

The Bank: HSBC
Account No: 31456016
Sort Code: 40-26-01
Account name: Thyroid PAUK

Remember, of course, to give your full name and home address whichever way you decide to pay.

If you have any questions, please let me know. Thank you so much for supporting our cause.

HOW YOU CAN MAKE YOUR DONATIONS GO 28% FURTHER!

Thyroid Patient Advocacy (TPA) does vital campaigning work to help and support all those suffering with thyroid disease, non-thyroidal illness or thyroid related conditions by raising awareness of these diseases and raising the funding necessary to carry out these vital campaigns.

TPA does not receive any Government funding. Our work is funded solely from donations, the sale of our Information Packs, Calendars and other merchandise.

If you have found the information we have provided in our Information Packs, our website, our Internet Forum, or through our local Thyroid Support Groups helpful, and you would like to contribute towards the continuation of our work, you may wish to send a small donation. Every penny is gratefully received.

GIFT AID

Through Gift Aid and Transitional Relief, you can help us make your donations go 28% further and the good news is….it won't cost you a penny!

How does Gift Aid work?

So long as you are a UK taxpayer, Gift Aid enables you to boost the value of your donations by 28p for every £1 you donate (25p in Gift Aid and a further 3p in Transitional Relief) to the charity of your choice, e.g. if you donate £10 to TPA, we will be able to reclaim an extra £2.80 from HM Revenue & Customs.

If you are a higher rate taxpayer, you are entitled to claim tax relief on your donations, enabling you to reclaim as much as 25p from every £1 donated to the charity of your choice.

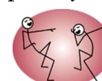
What do you need to do?

To donate through Gift Aid, you need to complete a simple declaration (orally or in writing) confirming that you are a taxpayer and that you are happy for Thyroid Patient Advocacy to claim tax relief on your donation. One declaration only will cover all donations that you have made to TPA over the past 6 years and will also cover any forthcoming donations you make, until you notify them otherwise.

To donate and to complete the Gift Aid Declaration form please click here

http://www.hmrc.gov.uk/charities/appendix_b1.pdf

My doctor gave me two weeks to live. I hope they're in August. *Ronnie Shakes*



DONATING TO OUR CAUSE

If you, or someone you know would be interested in donating to our cause, one way you can do this is to complete the form below and send it to Sheila Turner, Squirrel Cottage, Ickornshaw, Cowling, Nr Keighley, BD22 0DH. Yorkshire.

Alternatively, you may wish to set up a Standing Order (see details below).

Donor Information (please print or type)
Name
Address
Town
County
Post code
Telephone
(home)
Telephone
(business)
Fax
Email

I/we wish to contribute a total of £ .... to be paid now / monthly / quarterly / yearly
I / we plan to make this contribution in the form of:
Cash/Cheque/Direct Bank Transfer/Paypal

You can make a donation through Paypal to sheilaturner@tpa-uk.org.uk

You can create a Standing Order or Direct Debit to be paid to TPA-UK Account (details below)

The Bank: **HSBC**

Account No: **31456016**

Sort Code: **40-26-01**

Account name: **Thyroid PAUK**

You should make cheque payable to: **Thyroid Patient Advocacy** and send to above address

Thank you sincerely for supporting our cause!

Acknowledgement Information:
Please use the following name(s) in all acknowledgements:
I / we wish to have my / our gift remain anonymous.
Signature(s)
Date

FACTS ABOUT NATURAL DESICCATED THYROID EXTRACT

Because the majority of medical practitioners know little or nothing about natural desiccated thyroid extract, or who have misleading and incorrect information which they have been given by the British Thyroid Association, you may wish to print off a copy of the following document and send it to your GP or endocrinologist.

Dear Doctor

FACTS ABOUT NATURAL THYROID EXTRACT (ARMOUR THYROID, ERFA 'THYROID', NATURE THROID AND WESTHROID)

There are serious misconceptions amongst the medical profession concerning the use of Natural Desiccated porcine Thyroid extract (NDT) such as Armour Thyroid, Erfa 'Thyroid' Nature Throid and Westhroid as an alternative to levothyroxine (T4) -only, where a significant number of patients and their medical practitioners find the synthetic product to be ineffective in restoring their optimal health.

Although the following information may not be relevant to your current patients, I would urge you to keep it for reference for the benefit of any future patients who do not thrive on T4 only. Thyroid extract is often the most suitable medication for patients who complain of feeling unwell, even though their Thyroid Function Tests may show acceptable levels of hormone whilst taking T4 only.

Thyroid patients are desperately seeking an understanding and partnership with their NHS doctors to get the best treatment possible. We believe that every patient has the right to optimal treatment. Given that a number of thyroid patients do not respond well to thyroxine alone and continue to have many of the debilitating clinical symptoms of hypothyroidism, we feel that NHS doctors should be made aware that they *can* prescribe natural thyroid extract within the NHS to those patients who do not regain their normal health on thyroxine.

There are a number of misconceptions about NDT which we would like to rectify, as it is important that all medical practitioners are given the correct information.

1. Medical Practitioners believe they cannot prescribe NDT UNTRUE

Armour Thyroid, Nature Throid, Westhroid and Erfa 'Thyroid' are the brand names of natural, desiccated porcine thyroid extract. Branded NDT is authorised by the United States Federal Drug Administration (FDA) as medicine that is standardised to the specification of the United States Pharmacopeia. The Medicines and Healthcare Products Regulatory Agency has not objected to the importation of NDT, as it is an FDA authorised prescription medicine, standardised to the USP and is for the treatment of patients with thyroid disease, for whom the UK licensed thyroxine is unsuitable. Consequently it can be prescribed to patients who need it, subject to it being prescribed by a doctor. Please see letter and Emails from MHRA to TPA regarding this.

2. Thyroid extract quality is not consistent - UNTRUE

On their respective websites, the British Thyroid Association and the British Thyroid Foundation suggest that:

"*Armour is prepared from desiccated animal thyroid and the preparation and purification of this product may not be at the same rigorous standards of more modern medications*"

This is either erroneous or a deliberate attempt to mislead UK medical practitioners and patients.

Forest Pharmaceuticals, the manufacturer of Armour Thyroid, state that the amount of thyroid hormone present in the thyroid gland may vary from animal to animal. To ensure that Armour tablets are consistently potent from tablet to tablet and lot to lot, analytical tests are performed on the thyroid powder and on the tablets to measure actual T4 and T3 activity. Different lots of thyroid powder are mixed together and analysed to achieve the desired ratio of T4 to T3 in each lot of tablets. This method ensures that each strength of Armour will be consistent with the USP official standards.

The current USP monograph for thyroid tablets has

- an Assay to measure the quantities of liothyronine (T3) and levothyroxine (T4),
- a content uniformity test,
- a disintegration test and
- microbial limits.

Standards are set by an expert committee with open public comment. You can see citations to two references that discuss the stability of thyroid tablets and preparations at http://www.armourinfo.freeuk.com/document_1.html The first paper does not indicate that stability or uniformity were major issues in thyroid preparations. Copies of these papers can be obtained, as well as copies of the USP monograph on Thyroid Tablets from any medical or pharmacy school library.

3. **Armour Thyroid, Nature Throid, Westhroid and Erfa 'Thyroid' are made from bovine extracts - UNTRUE**

We contacted the Drug Information Pharmacist of the Professional Affairs Department at Forest Pharmaceuticals, who state that Armour Thyroid comes from United States grain-fed domestic pig thyroid. The thyroid extracts do not come from bovine thyroid. The reason some confusion may have arisen could be because many years ago, the manufacturers did produce a thyroid product, called 'Thyrar' (not to be confused with Thyrolar), that was made from bovine thyroid.

The disease status of porcine animals born, raised, and slaughtered in the USA or Canada can be accessed through the World Health Organization, Office Internationale des Epizooties (OIE) website at http://www.oie.int Here you will find that the USA and Canada are classified as being free of List 'A' porcine diseases including foot-and-mouth disease, swine cholera, swine vesicular disease, and African swine fever. This disease information can also be confirmed through United States Department of Agriculture USDA Animal Plant and Health Inspection Service (APHIS). Armour is a natural preparation of USP grade desiccated thyroid powder derived from porcine thyroid glands.

The above named NDT meets all the requirements set by the USP for thyroid medications and manufacturing specifications are tightly controlled, contrary to the BTA and RCP's current misconceptions about desiccated thyroid. The natural porcine thyroid powders are not sterile products nor are they designed to be such. The finished lots are tested for, and meet all USP compendial requirements, including those for the absence of Salmonella and E.coli pathogens. The manufacturers also verify that the Total Aerobic Plate Count (TAPC) does not exceed 10,000 Colony Forming Units per gram (CFU/g). The entire thyroid process is performed in accordance with the FDA Current Good Manufacturing Practices (cGMP) requirements. After processing, the thyroid products are packaged, stored, and handled in a manner to prevent any cross-contamination.

SO WHY THE CONTINUED MISCONCEPTIONS?

The BTA Statement on natural desiccated porcine thyroid extract has incorrect information regarding the reasons why NDT is not currently licensed in the UK. They also give out incorrect information about the reason NDT was withdrawn after synthetic thyroxine had been developed in the 1970's. This was NOT due to quality control problems; the suggestion that it was is blatantly untrue, and there are NO studies to support it.

In the United States, Armour and several other thyroid medications were 'grandfathered' in when the US Congress passed the Kefauver-Harris Drug Efficacy Amendments of 1962, to tighten control over drugs. Before marketing a drug, firms had to prove safety and effectiveness for the product's intended use. The requirement was applied retroactively to 1938, when the Federal Food, Drug, and Cosmetic Act was passed. Pre-1938 drugs were allowed because they were generally recognised as safe and effective, provided no evidence to the contrary developed. Too much evidence to the contrary developed concerning the levothyroxine products and the FDA decided none was generally recognised as safe and effective, so these synthetic products lost their 'grandfathered' privilege and had to go through the New Drug Application process. The NDT brands mentioned here **retain their 'grandfathered' status since no evidence to the contrary has developed concerning their safe and effective status.**

As NDT has never been licensed in the UK, it has never been withdrawn. The fall in demand was the result of assertions by certain drug manufacturers and medical authorities that the synthetic thyroxine was, by definition, better, and that porcine thyroid was greatly inferior. There have been NO studies to support this and BTA are seriously in error when making these assertions.

Interestingly, in a 1980 study, a number of generic versions of desiccated thyroid were found to be unreliable in potency. The amounts of T4 and T3 in Armour, on the other hand, were found to be constant (ref 1). Moreover, two-year old tablets of Armour Thyroid contained similar amounts of T4 and T3 as did fresh tablets.

The following quote from the bible of thyroid treatment, Goodman and Gilman's "The Pharmacological Basis of Therapeutics", sheds some light on this question. The reason why 'other' brands of desiccated porcine thyroid extract were withdrawn is:

" *Several years ago (1963), a large batch of material came into the hands of a number of distributors in the United States and Europe and, although of proper iodine content, it later proved not to be thyroid extract at all. This episode gave desiccated thyroid a bad name because several publications about the unreliability of thyroid extract appeared before the hoax was uncovered*".

A further allegation from the BTA state that the use of NDT causes "*substantial fluctuations to T3 levels*". This is once again quite unsupported by evidence. Doctors using NDT have found that over time T3 levels sometimes rise to a small degree without any significant consequence. The assertion that these so-called minor variations in T3 can cause strokes and osteoporosis is again completely without foundation or supportive evidence.

We are all aware that over dosage with T4 and T3 is undesirable, but NDT is no more likely to cause such problems than is synthetic T4 and T3. Splitting the daily dose would obviate any potential concern about transient elevations of T3 levels.

All thyroxine, whether made by the thyroid itself, or given exogenously, has to be converted to the active T3; and the thyroid produces just the right combination of T4 and T3 (as well as T2 and T1 and other unspecified hormones) that are available in NDT. Since T4 and T3 have been released together by the thyroid gland in all mammals (and many other species) throughout evolutionary history, it is absurd for the BTA to suggest that this combination is potentially damaging. **Desiccated thyroid has been used for a century in hypothyroid patients with great benefit and no harm**, and the suggestion, again by the BTA that the long-term effects are not known are incorrect. This is how nature does it and natural thyroid extract is almost identical to human thyroid.

WHERE NEXT?

Despite an extensive literature search we can find no scientific evidence to support the opinion that synthetic thyroxine is superior to natural desiccated thyroid extract. These studies have quite simply not been done. The logic of supplementing a failing thyroid has to be that it is as close to nature as possible; giving T4 alone is not and accounts for the unsatisfactory results in many patients. There is a growing body of scientific evidence that shows that many patients often do not regain a true sense of well being on pure synthetic thyroxine and prefer NDT because it works and actually makes them feel better. It is also quite untrue for the BTA to suggest that blood testing in patients taking NDT is less than satisfactory; indeed, it presents no difficulties of any kind.

It appears that there has not been ANY attempt to empirically evaluate the evidence regarding the use of thyroid extract. Its wholesale dismissal by the BTA and RCP represents, at least in part, a biased attitude. TPA would like to see the instigation of a properly conducted prospective randomised control trial as soon as possible.

Hypothyroidism is one of the few medical conditions where people are being refused a choice of treatment if the one and only levothyroxine therapy doesn't make them well. Hypothyroidism is also one of the few medical conditions where people are joining Internet support groups to find the information being denied them by their doctor. The current situation, whereby hypothyroid patients are being left to self-diagnose, self-treat, and self-monitor because most practitioners are unwilling to consider alternative medication, owing to their misconceptions about NDT is unacceptable.
There are valuable lessons to be learned by endocrinologists and GP's on these support groups.
Since natural desiccated porcine thyroid extract has been available since 1894, long before synthetic T4, and has been making patients better, it is up to such medical authorities to PROVE on the contrary, that synthetic T4 is as good, safe and reliable as Armour.

We are seeking to work in partnership with our medical practitioners to get the best treatment for hypothyroid sufferers. Getting the correct thyroid medication for the patient improves quality of life, and has helped many sufferers to return to work, relinquish state benefits and contribute towards the nation's wealth.

If Armour thyroid were labelled as USP it would be expected to meet the requirements of the USP monograph throughout its shelf life. The current USP monograph for thyroid tablets has an Assay to measure the quantities of liothyronine and levothyroxine, a content uniformity test, a disintegration test and microbial limits. Standards are set by an expert committee with open public comment. Citations to two references that discuss the stability of thyroid tablets and preparations can be seen at http://www.armourinfo.freeuk.com/document_1.html The first paper does not indicate that stability or uniformity were major issues in thyroid preparations. Copies of these papers as well as copies of the USP monograph on Thyroid, Thyroid Tablets can be seen at any medical or pharmacy school library.

Idis and Pharmara, as importers and suppliers, have to prove that Armour Thyroid, Erfa 'Thyroid', Nature Throid or Westhroid is being supplied for the permitted indication, and a spokesperson for Idis and Pharmarama has agreed that doctors now only need to write on the prescription "required for the treatment of hypothyroidism".

PLEASE SEE THE LETTER RECEIVED FROM MHRA on the TPA website. **http://www.tpa-uk.org.uk/mhra_letter.php**

I would welcome your suggestions as to how we might work together to increase general awareness and understanding of the issues

TPA CONFERENCE, BIRMINGHAM, SATURDAY 2ND OCTOBER 2010

This is the first year we have organised one of our TPA Conferences outside of Yorkshire. Because we realised that there were many people 'down South' who were unable to travel all the way to 'up North' and vice-versa, it was agreed we would try a venue in Birmingham – and very glad that we did. The meeting went splendid and a good time appears to have been had by all. That weekend I will remember because most of us staying overnight travelled to Birmingham the day before, from every corner of the UK in quite atrocious weather conditions with horrendous rain and high winds, causing many traffic jams on most of the motorways. This was not a good start.

However, Saturday dawned bright and clear and we made our way to Chung Ying Gardens Chinese/Thai Restaurant situated in Chinatown, right in the centre of Birmingham. It was a real pleasure to meet so many of you for the very first time, and good to meet up again with those of you who have attended our meetings in Yorkshire.

To read all about what went on and to listen (or read) the speeches given by Dr Peatfield, Dr Mantzourani, Dr Skinner, Nick Foot, Sheila Banks, plus my introduction etc., - and to learn more about where we have arranged our next Conference (The Black Horse Hotel, Skipton, North Yorkshire 11th June 2011) then please go here http://www.tpa-uk.org.uk/birmingham_conference_2010.pdf to book a place for yourself plus guest(s) as early as possible as these events are becoming extremely popular with our members.

THE IMPORTANCE OF REGISTERING YOUR THYROID STATUS IN OUR REGISTER OF COUNTEREXAMPLES TO LEVOTHYROXINE (T4) ONLY THERAPY

We cannot state strongly enough how important it is that if

- you had continuing symptoms of hypothyroidism whilst receiving levothyroxine-only therapy,
- and then started using a T3 containing hormone, either synthetic or natural thyroid extract
- and found your symptoms were alleviated or disappeared
- and you started to return to optimal health,

then please complete this questionnaire which consists of three very short questions. All you need to answer is either 'YES' or 'NO'

http://www.tpa-uk.org.uk/register_of_counterexamples.php

You do not have to give your name and address if you don't wish to do so, but being willing to testify to your experiences would help our cause enormously.

The objective of this questionnaire is to draw to the attention of responsible authorities to the urgent need for a re-examination of the existing protocol for the diagnosis and management of the symptoms of

hypothyroidism.

Through this register, we can prove to the medical establishments, both in the UK and throughout the world that levothyroxine-only therapy does NOT work for everybody, as their flawed studies show. We have to make the masters of endocrinology listen for the sake of all sufferers. Already, we have more people who have registered their thyroid status to show they need some form of T3 in order for them to regain normal health, than the participants who took part in those clinical trials, which showed a combination of T4 and T3 was no better than T4 alone.

Believe me, it is an absolute FACT that nobody else is going to help you get better treatment for your symptoms apart from yourself, so take this opportunity to help yourself, and help others, by completing the questionnaire.

I would mention that at our last TPA Conference in Birmingham, I asked the audience to put their hands up if they had continued with symptoms when using T4 only, but had regained their health when adding some form of T3. A lot of hands went up. I asked them to raise their hands again if they had not completed the questions and again, a lot of hands went up. PLEASE, PLEASE, PLEASE, DO COMPLETE THESE QUESTIONS. We need hundreds of people to make the medical profession sit up and listen and we DO HAVE THE POTENTIAL to get thousands world-wide but we have to rely on you to play your part.

The creation of such a Register of Counterexamples is one thing that will most definitely make a difference, where other actions taken on behalf of TPA, by Eric Pritchard and I, have failed. To give you an idea of the importance of this Register, I am listing what we have been doing behind the scenes below.

After reading this, please will you play your part by writing to your local MP to show him/her also what we

are doing, particularly in the light of all the rejections that we have received over the years from the UK Government i.e. Dept of Health, Office of Fair Trading, The Human Rights Commission, Liberty, the Charities Commission etc. not forgetting the Royal College of Physicians (London) and the British Thyroid Association etc.

In the beginning, Eric complained to the American Association of Clinical Endocrinologist, twice. He received just one reply, to tell him that they were the experts.

He then complained to the

1. Federal Government:
2. National Institutes of Health (3 institutes)
3. Agency for Healthcare Research and Quality
4. Office of Research Integrity
5. Secretary of Department of Health and Human Service
6. The Surgeon General
7. The Justice Department
8. The Federal Trade Commission (FTC)
9. The Food and Drug Administration (FDA)
10. The US Attorney General
11. Several US Senators and Representatives
12. Civil Rights Agencies

Most of the responses he received said they were sorry for his wife, but there was nothing they could do. The Food and Drug Administration rejected his petition to label levothyroxine sodium properly. The FTC appeared serious, initially, but then dropped the ball...

Then Eric thought that this was a State issue so he complained to

1. Governor Manchin several time even pleading for mercy for these unfortunate souls
2. West Virginia Board of Medicine
3. WV Dept of Health and Human Resources
4. WV Attorney General
5. WV Secretary of State

WV legislators including chairmen of DHHR oversight committee

Eric received a lot of "NO" answers and 5 rejections. His papers have been turned down by Medical Journals, although Dr. Lowe published one, but rejected others. Eric contacted other owners of thyroid web sites and forums in the past to see if they would help, but tells me that TPA was the only one who responded positively. We then began complaining to UK entities

We complained to

1. Department of Health
2. NHS Constitution
3. NICE
4. Human Rights Commission
5. The Charities Commission
6. The Office of Fair Trading
7. The Solicitor General
8. All NHS Endocrinologists
9. Head of all UK Medical Schools
10. The Queen
11. The BTA
12. The RCP
13. The owners of other thyroid web sites and Internet forums.
14. Other endocrinology groups...

We received mainly negative responses through prepared pro-forma letters which Departments use whenever complaints are received leaving them 'wriggle room' to actually do nothing. Many didn't even have the courtesy to respond, some endocrinologists responded quite positively, but some were extremely ignorant, arrogant and downright rude.

Eric and I now believe the thrust has been changed from some sort of rapid change initiative, to a slow change effort by convincing medical practitioners. The problem is that doctors are afraid of the General Medical Council and will not stick their heads above the parapet. They are, or should be, afraid of sham hearings at the GMC. They will never bring change until the supporters of the levothyroxine-only are dead and gone. But then, the first time the T4-only therapy was noticed to fail and published in a journal was 1947. It takes a little time for some knowledge to sink in! We suspect that there are a lot of medicines that are sold that could be replaced with proper care in the whole of the endocrine system, not just the little bit that is known classically.

So where does one get a fair and honest look at this? Eric believes that there are only two places, the law courts, and potentially, in the US, the attorney general offices. The Attorney General of Connecticut took on the Infectious Disease Society of America for the

unscientific process that happened to benefit some insurance companies - anti-competitive, patient abusing issues. The Attorney General in the UK fulfils a number of independent public interest functions. TPA has yet to contact the AGO to determine how he may help the TPA and will do so in the new year.

The whole T4-only therapy hypothesis rests upon numerous "studies" that claim the active hormone, T3, is ineffective, while the relatively inactive pro-hormone, T4, is effective. There is only array of events that can make this possible:

1.The subjects had only deficiencies in, or of the thyroid gland, for example it was removed.

2.The therapeutic dose of T3 provided was less than the dose of T4 taken away. Figuring in conversion efficiency, that value is about 3:1. But the ratios used in the various tests were 5:1, 10:1 and even 14:1

3.The T3 dose was routinely less than the starting dose for T3 per the New Drug Application for Cytomel (synthetic T3).Application for Cytomel (synthetic T3).

But then the interpretation of these studies hinges upon the definition of "hypothyroidism" and "thyroid." Are they broad or narrow. Well, these studies were done with the narrow definition, but to play it safe, doctors read it with the broad definition, as anyone would do playing it safe around regulators.

But, these studies have the basic problem of not being valid in the realm of broad interpretations, because there are counterexamples. Logically, those studies can only apply to the narrow definition of hypothyroidism - deficiency of the thyroid gland secretion. Logically, physicians should be able to treat the peripheral thyroid hormone deficiencies of inadequate conversion and inadequate reception. But they do not.

Right now, what is needed is for you to complete this short survey http://www.tpa-uk.org.uk/register_of_counterexamples.php if you felt better using synthetic or natural T3 instead of synthetic T4-only.

As Eric says "Have a great day" – and don't forget to write to your MP

HYPOTHYROID PATIENTS PETITION FOR A BETTER DIAGNOSIS AND CHOICE OF TREATMENT PROTOCOL

Please sign the online petition at this link

http://www.intlhormonesociety.org/index.php?option=com_content&task=view&id=31&Itemid=53&tomHack_idp=10

An Alternative Medical Dictionary: [Submitted by Nigel Morris]

Artery - The study of paintings.

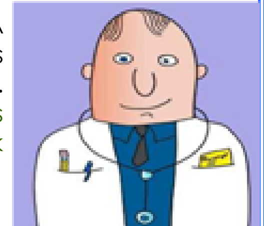
Barium - What Doctors do when patients die.

Caesarean Section - A neighbourhood in Rome.

Cauterize - Made eye contact with her.

Dr PEATFIELDS 2011 METABOLIC CLINIC

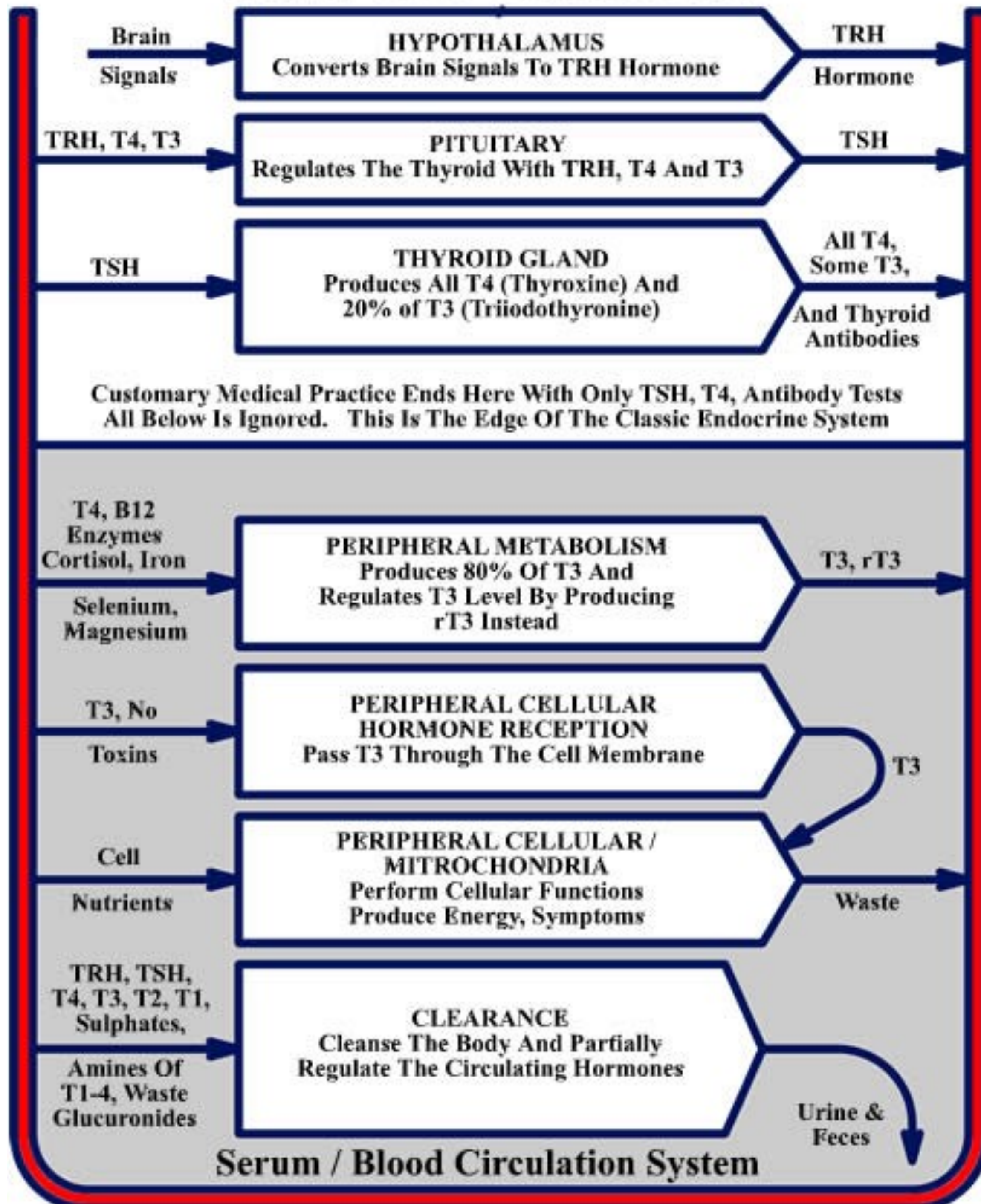
has been updated on the TPA web site showing all venues and dates available for 2011. Because of the popularity of his clinics, it's advisable to book early.



http://www.tpa-uk.org.uk/drpeatfield_clinics.php

The Greater Thyroid System - Information for Your Doctor

Many patients are being denied adequate relief from the symptoms of hypothyroidism because less than half of the greater thyroid system is being considered by physicians. And even that half is not fully tested if the thyroid-stimulating hormone is "normal." This chart illustrates the flow through this system starting at the top of the chart with signals from your brain to the bottom of the chart where the symptoms are sensed. As you can see, there are many functions after the *Customary Practice Laboratory Tests*. There are tests for these many functions, but they are not recognized. There are therapies for these functions, but they are banned by medical practice. Nonetheless, they are available.



PETER WARMINGHAM'S PAPER ON THYROID STIMULATING HORMONE

If your endocrinologist or GP insist on reducing your thyroid hormone replacement because your TSH level is suppressed, then please read this valuable paper written by Peter Warmingham, print it out and send a copy to your doctors with a request that s/he read it before deciding whether or not to reduce your thyroid hormone replacement.

http://www.thyroidscience.com/hypotheses/warmingham.2010/warmingham.7.18.10.pdf

"Hypothyroid patients whose thyroid hormone replacement dose is being regulated against the TSH reading alone are being maintained in an under-treated state and are correct to assert that they feel better on a higher dose. Therefore, hypothyroid patients should not have their thyroid hormone dosages set by reference to their TSH readings.

The TSH reading alone is valid only when the patient is not on thyroid hormone replacement therapy, but even then, there are two levels of inference between it and the thyroid hormone levels in cells, other than the pituitary thyrotrophs. Within the double inference there will be many interpretation errors.

The sensitivity of the TSH reading varies relative to the set point, and is least sensitive in the region of the set point"

Be prepared to fight your corner by asking your doctor to work with you, not against you. If necessary, be prepared to remind him of 'the duties of a doctor registered with the General Medical Council' http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp **part of which states:**

- Work in partnership with patients
- Listen to patients and respond to their concerns and preferences
- Give patients the information they want or need in a way they can understand
- Respect patients' right to reach decisions with you about their treatment and care
- Support patients in caring for themselves to improve and maintain their health

Patient: It's been one month since my last visit and I still feel miserable.
Doctor: Did you follow the instructions on the medicine I gave you?
Patient: I sure did - the bottle said 'keep tightly closed.'

ANOTHER WAY YOU CAN HELP US!

Have you been point blank refused a trial of a combination of synthetic T4/T3, T3 alone, or natural thyroid extract and told that there is no reason for anybody to need a T3 containing product, and that levothyroxine (T4)-only works for everybody? If this has happened to you and you have been left on T4-only that did not alleviate your symptoms, please would you write to me privately at sheilaturner@tpa-uk.org.uk giving the name and address of your local Primary Care Trust. We would then be in a position to write to the Trusts concerned asking for specific answers to be given to our specific questions. If we can prove that there is a definite failure in the treatment of those suffering the symptoms of hypothyroidism in 2 or 3 Trusts (more if possible) affecting 6 (or more) sufferers, then our lawyer has indicated that this may give us grounds for taking this matter further.

If you trust Google more than your doctor than maybe it's time to switch doctors.

SUPPLEMENTS HELPFUL FOR HYPOTHYROIDISM

Iodine

In the past, iodine deficiency was the main cause of hypothyroidism. Iodine is necessary for the production of thyroid hormones. It is chemically bound to a specific amino acid responsible for the formation of the base structures for both T4 and T3. A deficiency in iodine causes a deficiency in thyroid hormone production, which often results in the development of hypothyroidism. Supplemental iodine is beneficial for patients with hypothyroidism. It may boost the production of thyroid hormones by providing more base materials.

Selenium

Selenium is the main co-factor for the enzyme responsible for the conversion of T4 to T3 in the peripheral tissues of the liver, kidney, and skeletal muscle. This conversion accounts for the majority of the metabolism concerning T4. A deficiency in Selenium results in decreased levels of T3 in the blood, with normal to high levels of T4. However, there is usually enough of a disruption from normal homeostasis to cause hypothyroidism.

In one study of children who exhibited symptoms of hypothyroidism, a deficiency of selenium was recognized. After Selenium supplementation, hormone levels returned to normal and symptoms disappeared. Another study found that a low T3/T4 ratio in healthy elderly subjects could be corrected by supplementation

with selenium.

Zinc

The exact role of zinc in thyroid hormone metabolism is not completely understood, though it is viewed as a necessary component for proper thyroid function. Zinc deficiency has been shown to cause a decrease in T3, unrelated to thyroid production, and also a decrease in the conversion of T4 to T3. Zinc does not affect the levels of T4. In one particular study, Zinc supplementation for 12 months caused T3 levels in the blood to normalize in all participants, 75% of whom were found to be deficient in zinc.

Copper

Copper metabolism in the body is directly linked to zinc status. Supplementation with zinc can result in a copper deficiency, which can be dangerous. Therefore, when taking larger doses of zinc, supplementation with copper is also recommended. A shortage of copper causes red blood cells to be unable to make use of the iron available, so even if there is plenty of iron in the blood, the symptoms will be of anaemia.

Vitamin B12

Vitamin B12 is necessary for DNA and RNA synthesis, hormone synthesis, homocysteine metabolism, and is involved in function of the nervous system. Although the exact role of Vitamin B12 in thyroid hormone metabolism is not fully understood, it is believed to play a role in peripheral metabolism of T4 to T3. [4] Homocysteine is elevated in individuals with hypothyroidism. Another study found that not only homocysteine elevation was paralleled to a decrease in vitamin B12 in individuals suffering from hypothyroidism.

Folic Acid and Vitamin B6

Folic acid and B6 are also involved in homocysteine metabolism with Vitamin B12. To correct the increase homocysteine levels found in hypothyroid patients, the supplementation with all major nutrients is often needed. A deficiency of folic acid in individuals with hypothyroidism has also been reported in the literature of past study.

DHEA

DHEA is a steroid hormone precursor that is produced by the body. It has been found to potentiate the thyroid hormone activity in certain individuals. DHEA blood levels are decreased in patients with hypothyroidism. Although the exact relationship between DHEA and thyroid hormones is not completely understood, DHEA remains a legitimate treatment option for those with hypothyroidism.

LOCAL TPA THYROID SUPPORT GROUPS

Many people have expressed an interest in meeting other thyroid disease sufferers in their area and some have started to set up a local Thyroid patient Advocacy Support Group. If you are interested and would like to know more about these meetings, please would you contact the person running the one you are particularly interested in direct, or if you would like to set up a new group in your area, please let me know at sheila@tpauk.com and I will add you to our list and put the details on our web site.

Place	Name	Email
Bristol:	Delyth	p0shb1nt@yahoo.co.uk
Surrey	Maya	tangerine-
York:	John	marsaday1971@hotmail.co.uk
Manchester:	Shekha	shekhaomar@yahoo.com
Birmingham:	Glynis	arianrhod@supanet.com
Haslemere : (nearest town Guildford)	Lynda	lkay@sky.com
Derbyshire:	Karen	tinker-bell.3000@yahoo.co.uk
Chatham:	Denise	denib47@googlemail.com
London:	Julian	julianj@totalise.co.uk

DEMONSTRATION

A MARCH, a 'SIT IN' - or another Demonstration?

Will you let us know what your thoughts are about us organising a March, a Sit-in, or other form of demonstration to attract the attention of the media?

- Do you agree with such action?
- Would you take part?
- Could you help in the organisation?

We have opened a new Yahoo Internet Forum so interested parties can join to discuss this project. If you would like to join us, please let me know and we will send you an invitation **sheilaturner@tpa-uk.org.uk**

An Alternative Medical Dictionary:

Morbid - A higher offer.

Nitrates - Cheaper than day rates.

Node - Was aware of.

Outpatient - A person who has fainted.

Post Operative - Letter carrier.

Recovery Room - Place to do upholstery.

Seizure - Roman Emperor

Terminal Illness - Getting sick at the airport

Urine - Opposite of 'you're out'

NUTRTIONAL ADVICE FOR BREAST CANCER SURVIVORS

Dr Theodora Mantzourani

A post-menopausal woman was treated three years ago for an early breast cancer with surgery, chemotherapy and radiotherapy. She also received hormone therapy because her tumour was steroid-hormone-receptor positive. Her risk of metastasis has been evaluated as 25% at 5 years. Her current BMI is 32 and was 31 at the time of treatment. What type of dietary recommendations should this patient be given?

This patient was treated for cancer and is obese according to her current BMI. The dietary recommendations given to her should aim to reduce her risk of relapse and metastasis whilst lowering her BMI by reducing her dietary fat intake.

Dietary factors may influence the prognosis for breast cancer following diagnosis and treatment. Higher levels of energy, fat intakes, and selected patient characteristics (particularly disease stage and anthropometric indicators of adiposity) have been shown to increase risk of recurrence following the diagnosis of breast cancer (Saxe GA et al, 1999), especially in postmenopausal women (Zhang S et al, 1995). The Women's Intervention Nutrition Study (WINS) was the first large-scale randomized trial to test whether a dietary intervention of reducing dietary fat intake can improve the clinical outcome of women with breast cancer and showed that after approximately 5 years of follow-up, women in the dietary intervention group had a 24% lower risk of relapse than those in the control group (Chlebowski RT et al, 2006). The goal of the dietary intervention was to reduce percentage of calories from fat to 15% while maintaining nutritional adequacy which would result in a sustained reduction in fat intake to approximately 20% of calories (Chlebowski RT et al, 2006; Chlebowski RT et al, 1993). The rationale behind this concept lies in the fact that obesity and an increased recurrence with five units of BMI elevation reducing the risk of local recurrence after breast cancer conservative treatment by 0.66 (Marret H et al, 2001). The timing of weight gain has also been implicated as a risk factor for breast cancer recurrences (Kumar N et al, 1995). In any case, it appears that the dietary fat intake can modify breast cancer outcomes and an approach which would involve targeting identified individual lipids could be successful in lowering the metastatic risk (Bougnoux P, 2006).

The interaction between dietary fat reduction and hormone receptor status is another issue to be addressed with findings suggesting a stronger effect for dietary fat reduction on breast cancer recurrence in women with hormone receptor–negative cancers compared with women whose cancers were hormone receptor positive (Chlebowski RT et al, 2006).

The fatty acid profile of storage lipids to breast cancer survivorship indicate that diet could influence the metastatic risk by preventing tumor re-growth. Dietary PUFA, in particular DHA and CLA could be related to the prognosis of the disease. DHA sensitizes breast malignant tumors to anti-cancer agents and CLA (rumenic acid) has the potential to prevent tumor re-growth (Bougnoux P et al, 2009).

The action of CLA on metastases growth and development was found to be inhibitory of local tumor growth in mice with 1% of CLA in the diet (Visonneau S et al, 1997).It was also found to have a significant effect on the latency and metastasis of transplantable murine mammary tumors grown in mice fed with 20% fat diets (Hubbard NE et al, 2000). It has been found that the CLA isomer cis-9, trans-11 CLA, has an inhibitory action on chemically-induced mammary carcinogenesis in rats (Ip C et al, 1999; Ip C et al, 2002) and that 1% synthesized rumenic acid induced a 45% inhibition of tumor growth (Lavillonniere F et al, 2003). Furthermore, vaccenic acid, a rumenic acid metabolic precursor, produced equally efficient results (Banni S et al, 2001; Corl BA et al, 2003;

Lock AL et al, 2004). Moreover, it was found that on lung metastases growth and development, isomers cis-9, trans-11 and trans-10, cis-12 induced tumor inhibition (Hubbard NE et al, 2003). When tested *in vivo* though, no significant association was found between CLA level in adipose fat and either the prognostic factor (tumor size, nodal status, histoprognostic grade, mitotic index, and estrogen or progesterone receptors) or the risk of metastasis or death (Chajes V et al, 2003). Whether a CLA supplementation is justified in patients treated for localized breast cancer, in order to inhibit metastatic tumor growth would require more studies on medium sized animal models. Given our current knowledge and the availability of CLA as a 90% rumenic acid enriched mixture, CLA would require a prolonged cis-9, trans-11 CLA supplementation at a dose of 3.4 g/day in order to prevent breast cancer metastases. A daily amount of 3.4 g/day for two years is proposed, and it would be better to provide rumenic acid rather than the 50/50 mixture of synthetic CLAs (Bougnoux P et al, 2009).

Interestingly, inconsistencies in experimental results of dietary interventions with DHA on tumour growth in rats (Cogneaux et al.,2000;Maillard et al.,2006) may be attributed to interactions with other lipids or antioxidants leading to the concept of "lipidome" as an integrated approach of the ever changing lipid status or lipid profile of any individual adipose tissue at any particular time (P.Bougnoux,Guilford,2009). Like proteomics and metabolomics, the lipidomic profiling predicts the likelihood as well as the site of potential breast metastases but ,unlike the former, it may also be modulated by nutritional interventions making it an exciting novel strategy for public health in the cancer secondary prevention of the population. The lipidome is a composite marker of breast cancer risk and as such it is suggestive of a specific protective lipid profile against breast cancer relapse or metastasis- as opposed to a single fatty acid – which combines low levels of saturated fat and elevated omega3-and omega-6 fatty acids.

This exciting new approach would certainly benefit our lady in question as she would know exactly how to modify her risk of relapse and metastasis after her initial cancer treatment by making favourable changes to her lipidome through selective nutritional interventions: for instance cutting back on animal fats and increasing her intake of vegetable oils and fish oil as well as her consumption of fish and nuts. http://www.naturalnews.com/021230_doctors_physicians.html

…and a Christmas Message from Dr Jacob Teitelbaum

Dear Readers,

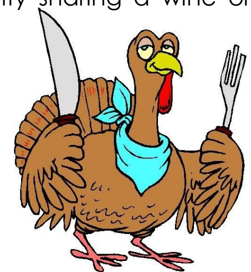
One of the values you've heard me preach is the importance of telling yourself it's OK to occasionally indulge the things you enjoy. In moderation, many of the foods and behaviors commonly held to be bad for you can in fact be quite healthy. Dark chocolate and the richness of antioxidants you get from eating it is one of my personal favorites. Having an alcoholic beverage now and then is another.

Though any discussion of alcohol starts and ends with a reminder to drink responsibly and in moderation, it's important to understand that alcohol does provide certain health benefits. In my newsletter I'll present some of new research that reinforces the "science of healthy imbibing."

With holiday parties just around the corner, it's nice to know you can feel a little less guilty sharing a wine or eggnog with your friends.

Love and blessings,

Dr. T



The Trustees wish all the members of Thyroid Patient Advocacy a particularly Wonderful Christmas and a very Happy Healthy New Year - with especial thanks to those members who have helped make our organisation such a success

…and here is a link to a Christmas Card to all members. Photograph taken by Kathleen Ranger with the Ode to TPA by Dave, Lilian's husband http://www.tpa-uk.org.uk/for_members/christmas_2010_card.htm