Spring / Summer Newsletter June 2010

Thyroid Patient Advocacy

Real Solutions for Real Suffering

Hello everyone, there's a lot of news and information in this particular Newsletter, so make yourself comfortable with a nice cuppa, put your feet up – relax and enjoy!

The TPA ANNUAL SPRING DINNER AND MEETING
The Alma Inn, Laneshawbridge, Nr Colne, Lancashire, 24 April 2010

Our annual spring meetings are proving an extremely popular event, bringing together members of our Internet thyroid support forum, our medical advisers, NHS doctors and others who travel from far and wide in order to attend.

In fact, they have grown so popular that we have arranged an autumn meeting on 2 October 2010 in order that those members from the Midlands and down South can attend - but more about this new venue later.
If you have not yet attended any of our previous meetings and would like to learn more about the work TPA-UK is involved in, you are very welcome and we would love to meet you.

Right to left: Sheila Turner, Dr Barry Peatfield, Dr Gordon Skinner, Gill Bell and John Bell

Sadly, Dr Theodora Mantzourani and her sister (also a doctor) were unable to attend as they had been stranded in Nice after attending a conference, unable to get a flight back to the UK because of the problems with volcanic ash. She will, however, be attending our October meeting as will Dr Peatfield and Dr Skinner.

The weekend started on Friday evening with dinner at The Dog and Gun (our favourite haunt) and well known by many TPAers staying in overnight accommodations. Saturday morning greeted us with blue skies and sunshine and by the time we arrived at The Alma, the majority of guests had arrived. The tables were set out beautifully and the room was full of laughter and chatter with everyone introducing themselves to each other. This year, we all wore name badges so we had an idea who we were talking to; it was good to put a face to the name.
When lunch was finished, I stood up to introduce Dr Barry Peatfield and Dr Gordon Skinner, but - I guess I got carried away. I have never given a speech in my life before, and when you listen to me – you will understand why. ☺

It's difficult to know when to stop, when one is so frustrated by this whole thyroid mess - which really is so unnecessary. We have to work to get it all sorted, but there are so many obstacles (some of these being active members of thyroid/endocrinology associations who should know better – but don't). I do think that a lot of the problems are caused because if you shout something loudly and long enough, even if it's a downright lie, the majority of the people will eventually come to believe that what you are shouting is true. You know the sort of thing "…*to reach a precise diagnosis of hypothyroidism, ONLY serum thyroid function tests should be used*…" or " … *all patients with hypothyroidism ONLY need levothyroxine sodium – they do not need T3*" or " …*if the TSH is within the reference range – wait for it…0.5 to 10.0 – the patient does not have a thyroid problem*".

There is no truth in such statements, yet mainstream doctors choose to believe them - and many are causing actual bodily harm to their patients

Listen to Sheila's speech

Dr Peatfield spoke about the great benefits of iodine, a subject that causes great controversy, especially in those who have autoimmune antibodies (Hashimoto's disease). He explained about the misunderstanding and misinformation about iodine and that, in fact, there is propaganda against it. He went through the history to the present day, and touched upon the subject of our need for unrefined salt. He pointed out that the evidence for reduction in salt in our diet is probably misplaced and that the problems really come from refined salt. Refined salt is actually not particularly good for us, because it's too simple, that is, too refined.

He pointed out that Dr Brownstein routinely uses Celtic salt, Himalayan salt and unrefined salts for people with low thyroid and low adrenal function. Dr Peatfield said he has found for himself some benefits and he has advised many people to come off this ridiculous 'no salt' regime, for their blood pressure. He believes the evidence for abstaining from salt is very, very thin, but all the doctors believe it . . . and believe it and believe it and believe it. He told us that he personally uses unrefined salt as it's much nicer, safer and it will actually help your thyroid/adrenal function.

Listen to the first part of Dr Peatfield's speech

Listen to the second part of Dr Peatfield's speech

Dr Skinner talked about many things that concern us all – and thank you Mike for doing such a great job with the editing. Dr Skinner is not shy about letting us know what he thinks about 'this whole thyroid mess' or about certain individuals/organisations who create this 'whole thyroid mess' and we had a good laugh, but on the more serious side, you will find his speech intriguing and enjoyable

He spoke also about the need for the formation of a World Thyroid Register to address the parlous situation of patients who are hypothyroid with no diagnosis, and indeed patients who are being managed with an unacceptably low level of thyroid replacement.

Dr Skinner's thoughts were that the situation has significantly worsened in the last year pursuant to pronouncements in the United Kingdom from the Royal College of Physicians and the Royal College of General Practitioners - who *inter alia* have suggested that patients should not be diagnosed with hypothyroidism if the TSH is less than 10.0 and moreover have declared that Armour Thyroid is a 'bad' preparation because the proportions of T4/T3 may not reflect the human proportions while contemporaneously suggesting prescription of T4 alone. This makes no sense at all.

He said that everything we have done has to date failed, including petitions with large number of signatures from hypothyroid patients and other concerned parties, numerous solicitations to various Members of Parliament, a plethora of letters to the BTA, BTF, SfE, RCP President (London), Heads of all Medical Schools, Office of Fair Trading, the Solicitor General, the Human Rights Commission, Liberty, the Charities Commission, the General Medical Council, the DoH, DHHS, NIH, AHRQ, FTC, DOJ, Secretaries of DHHS, <u>all</u> MP's (several times), without any action or response whatsoever, and all of whom do not seem to wish to embrace this matter. It's enough to make you want to give up, but we will never do that.

Dr Skinner made it absolutely clear that the only way forward is to form a World Thyroid Register with at least 50,000 signatories, who, at a future date, may be asked to contribute £20 or perhaps $30, which will be used to mount an effective campaign to redress this problem. For example: an appropriate complaint from a given patient on their own health problems to (perhaps) the General Medical Council which will ensure, through constitutional requirement, that the matter would, at last, be considered seriously.

The World Thyroid Register will consist of a list of completely confidential names.

Listen to Dr Skinner's speech

It may also be necessary, if the BTA/RCP folks continue to resist, and there is no final movement on this issue to see that medical justice is done, that we may need to consider legal redress. I believe that we have a great case to make for medical justice for the quarter million folks in the UK, against government offices, and certain medical offices, but we sincerely hope that this will not be necessary. However, at the end of the day, we cannot allow thousands of patients (millions worldwide) to be abandoned to a poor quality existence because of inexplicable obduracy among the medical profession and the medical establishment.

This 'hypo' problem could be the tip of a very large medical/pharmaceutical berg because T3 medicates so much in the body. For those who do not believe legal action is required, you should be aware of the universal rejection of FACT. **The diagnostic paper says it all. It can be found on the TPA web site.**

Some of our TPA members at the meeting

Not only is there a 13+% error rate in the therapy, there are an additional 6% of the population who never receive treatment - when they should. That number is far greater than the fraction of a percent (0.4%) that the 13+% is of the whole population

Dr Skinner says he cannot emphasise strongly enough that this register will not do anything else other than be a register, until there is a requirement for definitive action. He is particularly concerned that the leaders of groups, for example, presently established thyroid help groups, will be concerned, or think that he is trying to 'take over' their names. In fact, he emphasised that he would not wish to add the names of the members of any given help group, but merely an assurance, which is not binding, that if required, the chairperson will make appropriate contact with his/her group members.

The Register will thus have two kinds of members - namely those who have signed up to the World Thyroid Register, and members via affiliated groups from established organisations.

We must not allow what is happening to those suffering so unnecessarily to continue. We MUST do something now. **SO PLEASE, TAKE JUST A MOMENT TO SIGN DR SKINNER'S REGISTER HERE** **www.worldthyroidregister.com** and please ask your family and friends to sign it also.

The speeches were followed by a Question and Answer Session, which might have gone better had we had previous notification of questions so we could have prepared good responses, or the person asking the question had come nearer to the microphone.

Listen to the Question and Answer session

I do know that Mike spent hours editing this section, but some questions we couldn't hear, so if yours is not there, apologies. For our next meeting, we ask that all questions be submitted in writing, so that we can read them out for those unable to come to the microphone – this way, we will get a quality recording

THE RAFFLE

We organised a raffle to help raise money for TPA and placed a DONATIONS box on the raffle table. The raffle was a HUGE success with many thanks to, and, with the very generous donations, we raised **£450**. Thank you all so very much.

Raffle Prizes were donated by the following:

Handmade Swarovski Crystal Jewellery:
Lee Appleyard of Lee Appleyard Designs

Two Cream Handmade Cushions: *Amanda H*

CDs, Calendars etc: *Kathleen Ranger*

Original Oil (Bluebell Woods): *Sheila Turner*

Hamper: *Marie Holloway*

Silk Handbag: *Kimberley Werner*

£25 M and S Voucher: *Elizabeth MacDonagh*

Bottle of Whisky: *Ina Whitlam*

Signed book by the author: *Dr Barry Durrant-Peatfield*

Five signed books by the author: *Dr Gordon Skinner*

The PA system at The Alma had only been checked the night before, and sadly, found it to be not working, so we had to rely on Mike to do his best with his own equipment – which was actually fantastic. A BIG THANK YOU TO MIKE for all your hard work, and all your great patience when editing the recordings. I know how difficult that was.

Mike*, recording the speeches and Question and Answer Session*

. . . And then back to Squirrel Cottage . . .

After the meeting, many of the guests gathered at my home, Squirrel Cottage, for refreshments and gossip which was most enjoyable. It was a beautiful evening so many sat in the garden, whilst others enjoyed their food and drink indoors. Very many special thanks to Ina, who, for the second year running now has helped in 'the galley' and the final clearing up.

Left to right: Dr Ahmed, Dr Skinner, Mike Taylor, Dr Peatfield

Some of our TPA members at Squirrel Cottage

Have you seen our web site Home Page recently? If not, take a look. You will see that Lee has created a new header which tells the world more about our aims and objectives. We have also changed our Mission Statement to one where we are asking questions. Will we get any answers? We'll have to wait and see!

Call for Volunteers

James Appleyard, designer of the TPA web site and a Master's degree student in Web Applications Development at Leeds Metropolitan University, is seeking volunteers to take part in his degree dissertation.

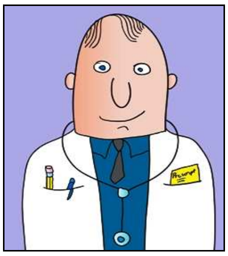
As part of his study into web site accessibility, James is looking to recruit those who use an alternative means to gain access to the Internet when they have any difficulty navigating it. This can include any assistive technology or additional means you might use to view your favourite web sites such as:

- screen readers
- screen magnifiers
- text browsers
- keyboard shortcuts
- speech recognition software
- text-to-speech software such as BrowseAloud
- Braille displays
- browser help such as text or screen magnification (zoom feature)
- any other forms of access technology you might use if you suffer from a medical condition that prevents you from easily accessing the Internet

If this is you, please get in touch with James at **james.appleyard@blueyonder.co.uk** as soon as possible.

Volunteers will just be required to pass on their experiences with regards to accessing and browsing websites and to carry out a few pre-defined tasks on a couple of websites and provide feedback their experiences of doing it.

All feedback will be anonymous, and you will have the opportunity to opt out before the end of August if you wish. Feedback will also be used for the redesign of the TPA web site.



Dr Peatfield's Metabolic Clinic Schedule has been updated on the TPA web site. There are currently new available dates at his usual locations, but because of the popularity of his clinics, it's advisable to book early.

Thyroid Patient Advocacy - CHARITY STATUS

I am delighted to tell you all that Thyroid Patient Advocacy was accepted and registered at Companies House last month.

All the papers have now been completed and sent to the Charities Commission (CC) for us to finally become a Registered Charity, which we expect should be happening very shortly.

The main benefit of becoming a charity is that funders are more inclined to give money to an organisation that is registered as opposed to one that is not. As the Charity Commission watches over the activities and accounts of charities, there is a certain level of trust and financial accountability. Registered charities also hold a certain level of trust with the public that other groups may not have. The government also views them differently and does all it can to help direct as much money as it can into their chosen cause. Let's hope they will give money to TPA as "their chosen cause".

As previously stated, we were advised that we needed to show we were capable of raising funds by raising an initial £5,000 I am really delighted to tell you all that between us, we have now already raised the magnificent sum of £8,988.84. A copy of our bank statement has been forwarded to the CC.

I mentioned at our Spring meeting that the trustees and I have agreed that money raised in the first instance should be dedicated to funding specific named projects/campaigns.

As some of you already know, we feel there is a great need for a European Hypothyroid Patient Survey to be undertaken to find out how different countries diagnose and treat those with the symptoms of hypothyroidism.   Hopefully, the results will highlight why it is that over 250,000 people in the UK alone are being left to suffer the symptoms of hypothyroidism so unnecessarily.

The cost of this project is expected to be in the region of £20,000 – so we are still looking for over £11,000. 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/Paypal**
- ***You can create a Standing Order or Direct Debit to be paid to TPA-UK Account (details below)***
- ***You can make a donation through Paypal to sheilaturner@tpa-uk.org.uk***

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

Acknowledgement Information:
Please use the following name(s) in all acknowledgements:

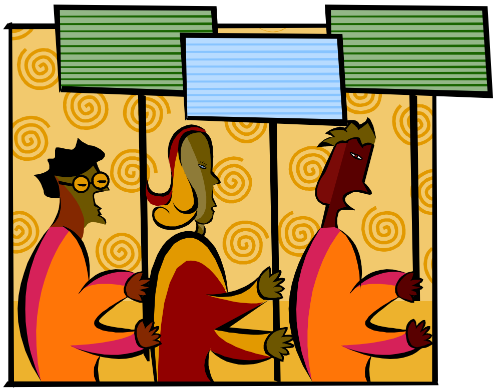
I / we wish to have my / our gift remain anonymous.

Signature(s)
Date

Please make cheque payable to: **Thyroid Patient Advocacy UK** and send to above address

Thank you for supporting our cause!

A MARCH – a 'SIT IN' - or OTHER 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?**

PLEASE LET ME KNOW
sheilaturner@tpa-uk.org.uk

GLOBAL ALLIANCE FOR THYROID TRUTHS

You may be pleased to know that another recent goal that is just getting off the ground is the formulation of a global alliance of like-minded International leaders of thyroid related sites starting with:

- Sheila (United Kingdom), from 'Thyroid Patient Advocacy' **www.tpa-uk.org.uk**
- Janie (USA), from 'Stop the Thyroid Madness' **http://www.stopthethyroidmadness.com/**
- Stephanie (USA), from 'Natural Thyroid Choices' **http://www.naturalthyroidchoices.com/index.html**
- Sara (Sweden) from 'Hypometabolism' **http://hypometabolism.ning.com/?xgi=1FvGEJutw0Wdl5andxg_source=msg_invite_net**
- Emise, also from 'Hypometabolism'

This is our 'Starter Pack' and once we have agreed our objectives, created our mission statement and are up and running, we will then be inviting other leaders, researchers, doctors, scientists to join us. Hopefully, such a union of like minds, working together, is what is needed to bring about the necessary changes.

Understanding Treatment of Lowered Metabolism

By Dr Barry Durrant-Peatfield

Contrary to cherished beliefs by much of the medical establishment, the correction of a thyroid deficiency state has a number of complexities and variables, which make the treatment usually quite specific for each person. The balancing of these variables is as much up to you as to me – which is why a check of morning, day and evening temperatures and pulse rates, together with symptoms, good and bad, can be so helpful.

Many of you have been ill for a long time, either because you have not been diagnosed, or the treatment leaves you still quite unwell. Those of you who have relatively mild hypothyroidism, and have been diagnosed relatively quickly, may well respond to synthetic thyroxine, the standard treatment. I am therefore unlikely to see you; since if the thyroxine proves satisfactory in use, it is merely a question of dosage.

For many of you, the outstanding problem is not that the diagnosis has not been made – although, extraordinarily, this is disgracefully common – but that is has, and the thyroxine treatment doesn't work. The dose has been altered up and down, and clinical improvement is variable and doesn't last, in spite of blood tests, which say you are perfectly all right (and therefore you are actually depressed and need this fine antidepressant). There are some good reasons for this, and I'm going to list them.

1. Your thyroxine dose is too low

Often this is the case, and the doctor or consultant won't increase it, since the blood levels appear perfectly okay. Sometimes, though, the dose of thyroxine is quite high – 200 mcg – 300 mcg – but you still don't feel well.

2. Partial response to the single synthetic thyroxine replacement

Your thyroid produces four other hormones apart from thyroxine, and most of us need them all. Without them our response is limited and synthetic thyroxine may not suit the system as well as the natural thyroid hormones.

3. Adrenal fatigue or exhaustion

This is very commonly met with indeed. The production of thyroxine (T4), its conversion to liothyronine (T3), and the receptor uptake (called 'binding') requires a normal amount of adrenal hormones, notably, of course, cortisone. (Excess cortisone can shut production down, however.)

4. Failure of the 5 dei-iodinase enzyme

This is what happens if the adrenals are not responding properly, and provision of cortisone usually switches it on again. But sometimes it doesn't. If the illness has been going on too long, the enzyme seems to fail. This conversion failure (in explicably denied by many endocrinologists) means the thyroxine builds up, unconverted. So it doesn't work, and T4 toxicosis results. This makes you feel quite unwell, toxic, often with palpitations and chest pain. (I refer to this further on.) If provision of adrenal support doesn't remedy the situation, the final solution is the use of the thyroid hormone, already converted, T3.

5. Receptor resistance

Being hypothyroid for some considerable time may mean the biochemical mechanisms which permit the binding of T3 to the receptors is downgraded; the T3 just won't go in. With slow build up of T3, with full adrenal support and adequate vitamins and minerals, the receptors do actually come on line again. But this can be quite a slow process, and care has to be taken to build the dose up gradually.

6. Food allergies

The most common food allergy is allergy to gluten, the protein fraction of wheat. The antibody generated by the body, by a process of molecular mimicry, cross reacts with the thyroperoxidase enzyme, (which makes thyroxine) and shuts it down. So allergy to bread can make you hypothyroid.

There may be other food allergies with this kind of effect, but information on these is scanty. Certainly allergic response to certain foods can affect adrenal function and imperil thyroid production and uptake.

7. Presence of systemic candidiasis

This is where *Candida albicans*, a yeast which causes skin infections almost anywhere in the body, invades the lining of the lower part of the small intestine and the large intestine. Here, the candida sets up residence in the warmth and the dark, and demands to be fed. Loving sugars and starches, candida can make you suffer frightful sweet cravings. (I wouldn't be surprised if it can synthesize a neurotransmitter, which causes such craving that you have to have chocolate, on pain of death.)

Candida can produce toxins which can cause very many symptoms of exhaustion, headache, general illness, and which interfere with the uptake of thyroid and adrenal treatment. Sometimes the levels – which we usually test for – can be very high indeed, and make successful treatment difficult to achieve until adequately treated. (More of this further on.)

8. Hormone imbalances

The whole of the endocrine system is linked; each part of it needs the other parts to be operating normally to work properly. An example of this we have seen already, with cortisone. But another example is the operation of sex hormones. The imbalance that occurs at the menopause with progesterone running down, and a relative dominance of oestrogen is a further case in point – oestrogen dominance downgrades production, transportation and uptake of thyroid hormones. This is why hypothyroidism may first appear at the menopause; the symptoms ascribed to this alone, which is then treated – often with extra oestrogen, making the whole thing worse. Deficiency in progesterone most especially needs to be dealt with, since it reverses oestrogen dominance, improves many menopausal symptoms like sweats and mood swings, and reverses osteoporosis. Happily natural progesterone cream is easily obtained: when used it has the added benefit of helping to stabilise adrenal function.

When you have been quite unwell for a long time, all these problems have to be dealt with; and since each may affect the other, it all has to be done rather carefully.

Why Iron Levels Remain Low

By Tony Pearce

With permission to copy given by Tony Pearce

http://www.femail.com.au/iron-levels-tony-pearce.htm

A low iron level is arguably the most prevalent nutritional deficiency in women of menstruating age. Iron is lost predominantly through menstruation each month, and if a woman's periods are excessively heavy or frequent, she may drop her iron storage (termed ferritin) quite rapidly. Iron deficiency may also occur during pregnancy as a result of increased demands on the mother's nutrient reserves by the developing infant.

Iron is central to healthy functioning of the human body because it is the main constituent of hemoglobin - the oxygen-carrying protein inside red blood cells. Iron is also essential for many bio-chemical processes including the formation of cytochromes and certain respiratory enzymes.

A small but constant daily intake of iron is essential to maintain the quality and numbers in red blood cell production. Females 14-50 years of age require 15-18mg of iron per day, decreasing to about 8mg/day after menopause.

When iron levels are reduced, fatigue and intolerance to cold are often early indicators. Both symptoms are related to inadequate oxygen supply (due to decreased hemoglobin) vital for ATP and thermogenesis (heat) production. The revealing pallor of iron deficient women is again due to low hemoglobin content in the blood. Raising iron levels in a woman with iron deficiency anaemia can sometimes be a lengthy and exasperating process, for there are many factors to frustrate this undertaking. The main issues are:

1. **Blood Loss from bleeding ulcers, hemorrhoids, ulcerative colitis or other problems within the gastrointestinal or genitourinary tracts.** When iron levels fail to rise with iron supplementation, the patient should be referred (by their GP/MD) to a Gastroenterologist for further investigation - and exclude any malignancy.

2. ***Helicobacter pylori* infection** is - with the exception of blood loss - the most common cause of iron deficiency worldwide. *H. pylori* bacterium decreases the gut's ability to absorb iron by inhibiting gastric acid secretion, damaging the stomach's mucous layer, and underlying gastric cells. *Helicobacter* serology and/or a fasting C14 breath test should always be performed in chronic iron deficiency.

3. **Coeliac Disease/Gluten Intolerance** occurs in the small intestines of pre-disposed people as a result of an inflammatory reaction to gluten - the

main protein of wheat, rye and barley. Over time, the intestinal lining is obliterated, diminishing its capacity to absorb dietary nutrients - particularly iron. Coeliac serology should be mandatory when investigating the cause/s of iron deficiency.

4. **Intestinal Parasites and Disordered Gut Function**: *Blastocystis hominis* is a 'natural' inhabitant of the human gastrointestinal tract. However when over-colonisation of this parasite occurs, it can cause chronic diarrhea, fever, nausea and abdominal cramping. *B. hominis* utilises iron from the host's body to mature and replicate, thus depleting the person of iron for their body's needs. Many chronic anaemia patients are found to be infested with this parasite.

Severe fermentative dysbiosis is an overgrowth of normal gut bacteria due to inadequate gastric acid and/or pancreatic enzyme production. Sufferers often exhibit multiple nutrient deficiencies including iron, B group vitamins, B12, zinc and magnesium.

5. **Competing nutrients**: When supplementing vitamins and minerals, it's important to know which nutrients aid or antagonise another's absorption. Taking an iron supplement at the same time as the minerals zinc, or copper, or calcium or chromium will inhibit the absorption of all. Excessive or prolonged supplementing of Vitamin B12, D or E can inhibit the absorption of iron.

6. **Copper deficiency** may result in a refractory anaemia unrelieved by iron supplementation. A deficiency of copper hinders the deployment of iron by the red blood cells, resulting in the iron being accumulated (and unavailable) within the organs of the body. Because this stored iron cannot be utilised whilst the copper deficiency persists, symptoms of iron deficiency may present despite an actual iron sufficiency.

7. **Underactive thyroid function (Hypothyroidism)** is an indirect cause of low iron as the active thyroid hormone T3 (Triiodothyronine) is essential for good gut function.

8. **Heavy metal toxicity of lead, mercury or cadmium** will inhibit iron absorption and utilisation. Heavy metal poisoning now receives greater investigative focus due to its severe impact on people's health.

9. **Strenuous exercise** with a resultant heavy perspiring utilises iron, Vitamins B12, folate and protein at an accelerated rate. A demanding exercise regime may also lead to decreased nutrient absorption as blood supply to the gastrointestinal tract is diverted to the muscles. Excessive exercise/perspiration depletes zinc, magnesium, and often potassium. A good level of zinc is required for the stomach to produce hydrochloric acid (HCl), HCl is essential for the absorption of iron, magnesium and 'trace elements' (zinc, selenium, molybdenum, manganese, copper, cobalt, vanadium). Athletes who are iron or other nutrient deficient should rest or undertake very light workouts only, and replete with quality supplements.

10. **Iron combinations**: it's unclear why, but some people better absorb and utilise certain forms of iron and not others. Supplementing with different types of iron or an iron 'combination' may yield better results. Iron picolinate, ferrous fumarate, ferrous sulphate, or iron amino acid chelate are iron variations to be considered. Oral iron supplementation should be at least 80mg per day. Vitamin C and amino acid complex enhance the absorption of iron.

11. **Compliance, diligence, patience and time are essential pre-requisites** to rebuilding depleted iron stores. Patients will often take an iron supplement for three to four months only to find their iron levels are unchanged or even lower. This is due to low bone marrow iron that has compensated by taking iron from the muscles (myoglobin). When iron is being replenished through supplementation, the bone marrow "debt" to the muscles must first be repaid - hence iron storage (ferritin) remains static or even falls. This is a temporary setback, and the person's iron levels will eventually lift as they continue supplementing. At this time, it's important for the practitioner to reassure the patient, allay anxieties and encourage continued compliance.

About the Author:

Tony Pearce is a specialist trichologist and registered nurse. He is a founding member of the Society for Progressive Trichology and the official lecturer for Analytical Reference Laboratory (ARL) for hair loss and hormone imbalance. He is the Clinical Director for Trichology Hair Solutions of Virginia/DC in the United States. In Australia, he can be contacted on 02 9542 2700, or through his website at **www.hairlossclinic.com.au** .

References for this article available on request.

Do You Need to Make an Official Complaint About an NHS Service – But You Don't Know the Procedure?

**From 1 April 2009, the government has introduced a simpler,
two-stage process for complaints about NHS services**

First stage – local resolution

The first stage of the NHS complaints procedure is called 'local resolution' and aims to resolve complaints quickly and appropriately. If you want to complain about an NHS service, for example, a hospital, GP, or optician, you should contact them directly and speak to a member of staff. They may be able to resolve your concerns without the need to make a more formal complaint.

As well as speaking to those involved, you can contact the Primary Care Trust (PCT), hospital trust, or any other NHS organisation concerned. They should have a complaints procedure in place, and you should ask for a copy of it.

You can complain verbally or in writing. A large health centre will normally have a complaints manager. The manager should make a written record of your complaint. A smaller centre, or practice, may not have a complaints manager, but they will still have someone who is responsible for dealing with complaints.

Time limit

You should make your complaint as soon as possible after the incident happens. The time limit for a complaint is normally:

- 12 months from the date that the event happened, or
- 12 months from the date that you first became aware of it.

If you are complaining on behalf of someone else, the hospital or practice must agree that you are a suitable representative.

PALS and ICAS

The complaints manager can arrange for an independent organisation, such as ICAS, to help resolve the complaint. You can also contact these organisations yourself.

PALS (Patient Advice and Liaison Service) provide a confidential service that is designed to help patients get the most from the NHS. They can tell you more about the NHS complaints procedure, and they may be able to help you to resolve your complaint informally.

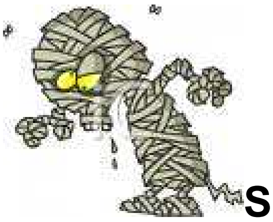
ICAS (Independent Complaints Advocacy Service) is a national service that supports people who wish to make a complaint about their NHS care or treatment. See 'further information' for more details about **PALS** and **ICAS.**

Second stage
Parliamentary and Health Service Ombudsman

If your complaint is not resolved successfully after local resolution, you can complain to the Parliamentary and Health Service Ombudsman (PandO). The Ombudsman is independent of the NHS and government. You can contact them by phone on 0345 015 4033 or you can email them through their website (see 'further information').

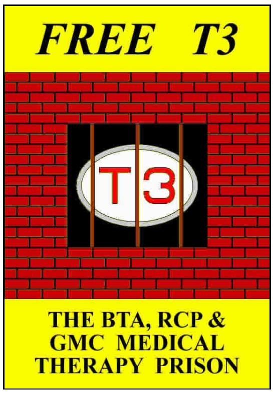
Further information:

What is the Patient Advice and Liaison Service (PALS)?
How do I make a complaint about my GP?
NHS complaints
Find your local Primary Care Trust
CAB: NHS and local authority social services complaints
Department of Health: NHS complaints procedure
Department of Health: ICAS
Department of Health: PALS overview
PandHSO: Changes to the NHS complaints system



A Message to the British Thyroid Association and the Royal College of Physicians et al from Thyroid Patient Advocacy

'FREE T3' from proscription by the Regulators of medical teaching and practice. The active thyroid hormone triiodothyronine (T3) replacements are approved by pharmaceutical regulation, yet the regulators, with the backing of medical councils and boards of medicine, prohibit medical practitioners from prescribing it - in spite of its vital necessity. **WHY?**



'FREE T3' is essential to life. The regulators refuse to recognise this. They have not and will not, properly recognise their failure to mitigate symptoms of hypothyroidism. They deliberately refuse to acknowledge the applicable and established medical science, which has been available for over 40 years and which demonstrates and expounds their failures. Instead of analysing their failures, they make excuses. For example, you are suffering from a functional somatoform disorder – "it's all in your head", or your symptoms are non-specific.

'FREE T3' is a slogan that stands for getting the proper diagnostics and medications for people suffering the symptoms of hypothyroidism, in spite of diagnoses that do not indicate thyroid dysfunction and therapies that are ineffective. The regulators are preventing medical practitioners examining on the basis of the whole of the Greater Thyroid System Chart. Consequently, doctors are completely unaware of the complexities and problems set out in this table. The regulators proscribe the primary hormone T3, and ban supplements of other essential hormones, promoting T4-only therapy.

COME AND JOIN US AT OUR AUTUMN DINNER AND MEETING

Saturday, 2 October at Chung Ying Gardens
17 Thorp Street, Birmingham, West Midlands, B5 4AT
12.00 noon until 5.00pm

幸福會議

Located in the heart of Chinatown, Chung Ying Garden is one of the largest and most popular Chinese restaurants in the Midlands

The link below takes you to a video presentation of the different rooms throughout the restaurant. The room we have booked is large, with round tables seating 10 people per table. The best pictures in the video that show the room we have booked are numbers 16 and 17. The room with the bar at the far end.

http://www.chungying.co.uk/en/Chung_Ying_Garden/Gallery.cy

We have our own bar which will be manned throughout our dinner and meeting, with our own toilets and even a 'smokers balcony' for those who feel the need. We also have our own PA system and large projection screens for the benefit of those sitting at the back of the room. The large room seats up to 80, but if there are more than this number attending, there are sliding doors at the side of the room that open up to an adjoining room, which seats a further 50 people. There is a large projection screen in that room too.

Sadly, there has to be a draw back. If you look at the first picture in the video, you will see there are about eight steps up from the street to the ground floor. There is a further wide flight of stairs up to the first floor. However, for those in wheel chairs, or those who find stairs difficult, James has assured me that they have "some big strong lads" who will be only too happy to help with the transportation of anybody from the street right to your table. They have apparently carried wheelchairs up on numerous occasions. There is no lift and no stair-lift, but once you are there, everything else is on the same floor.

There is plenty of car parking at the back of the restaurant, and plenty of other car parks around

the area, including the very large Bull Ring Centre car park, which is five minutes walk away.

However, some of you who are travelling by train will be pleased to hear that the New Street Station is about a 10 minute walk away, and if you need a taxi, this is a very short distance. There is a tram that will take you from Snow Hill Station to very near Chung Ying Gardens. By the way, there is also a 'sister' to Chung Ying Gardens, which is a smaller restaurant called 'Chung Ying' close by, so be sure to mention the '**Garden**'.

Lunch will be served at 12.00 noon sharp, after which, there will be speeches by Dr Peatfield, Dr Skinner and Dr Mantzouorani. After that, it will be open to a question and answer session. This time however, if you have any specific questions to ask, please write them down and send them to me at **sheilaturner@tpa-uk.org.uk** so we can be ready to hopefully find a satisfactory answer. Sometimes, it is difficult to be able to answer spontaneously, as we found at the last two meetings.

I visited the Chung Ying Gardens Restaurant to sort out the menu and I hope you will all be happy with it. For those who do not like spicy food or who have special dietary needs, James will be happy to accommodate these, but you must contact him nearer the time to discuss your wishes with him (0121 666 6622) and **speak to James ONLY.**

We have agreed to cut down the cost of the menu for our TPA party from £17.00 a head to £12.00 a head. You will pay for your meal at the end of the meeting and the cost of drinks, coffee/tea, puddings etc will be extra.

Chung Ying Garden Menu

Starters

Hot and Sour Soup
Vegetarian Spring Rolls

Main Course

Sweet and Sour Chicken
Beef in Black Bean Sauce
Fillet of Fish (Thai Style)
Sliced Lamb with Ginger and Spring Onion
Mixed Vegetables
Egg Fried Rice or Fried Noodles

These will all be served in bowls and brought to your table so that you can help yourself to whatever you like.

Please let Amanda know by emailing her at galathea@tiscali.co.uk if you would like to book a place for the lunch and meeting and let her know how many guests you will be bringing with you. This is very important as the accommodation will only seat just over 100 - so it will be first come, first served. Please note that it is expected that all guests will be taking lunch. The accommodation and service has been given to us free of charge on the understanding we will be all be eating, so please take note. That is, all you will be expected to pay, as we have made no charges to attend the meeting.

Also, with the great success raffling prizes to raise funds for TPA at our April Meeting, if you are would be happy to donate a raffle prize yourself for the October Meeting, **please contact Marie and let her know** **holloway.marie@googlemail.com**.

For those of you who will be coming some distance, below are some hotels and B and B accommodations. Central Birmingham hotels can be expensive, especially Friday and Saturday nights, but there are some cheaper (basic) hotels in the area.

Please be aware that the Conservative Party Conference is also being held on Saturday, 2 October, so book your accommodation early. There are several large hotels nearby, but being central Birmingham as well as Friday and Saturday nights, as you can imagine, the price can be high. The Ibis Hotel, which is very close to the restaurant is charging £95.00 per room per night! However, there is one hotel called The Etap and the room rates are the same for both Friday and Saturday: £55.00 per night per double room. This is a basic hotel but with good clean rooms for three people (with a bunk bed) plus flat screen TV, a comfort shower and separate toilet. Perhaps if quite a few stayed there, you could share a taxi(s) to the Chung Ying Gardens.

http://www.etaphotel.com/gb/hotel-5678-etap-hotel-etap-hotel-birmingham-centre/index.shtml

Here are a few smaller establishments that seem to have reasonable reviews:

Westbourne Lodge
27-29 Fountain Road
BIRMINGHAM
B17 8NJ
Telephone 0121 429 1003
www.westbournelodge.co.uk
Good standard of B and B, charges £85.00 per double room and £65.00 per single room per night. (Six rooms available) - Situated approx two miles from the New Street Station.

Elmdon Lodge Hotel
20-24 Elmdon Road
Acocks Green
BIRMINGHAM
B27 6LH
Telephone 0121 706 6968
www.elmdonlodge.co.uk
Again, good reviews, charges £65.00 per night for double room and £59.00 per night for twin room and has free parking. It is situated approx four and a half miles from the New Street Station.

Gables Nest Guest House
1639 Coventry Road
Yardley
BIRMINGHAM
B26 1DD
Telephone 0121 708 2712
www.guesthousebirmingham.co.uk
Good reviews - Has five double rooms and charges £50.00 per night - Four miles from the New Street Station.

* * *

Please sign this International Patients' Petition for Better Diagnosis and Treatment Choice for Hypothyroid Patients

http://www.intlhormonesociety.org/index.php?option=com_contentandtask=viewandid=31andItemid=53andtomHack_idp=10

Wildlife Calendars by Kathleen

Contact Kathleen at
kranger1@btinternet.com

A portion of all sales will go to TPA

Buy Anything from Amazon from our web site and TPA-UK receives 5% to help with our funding

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

TPA has joined Amazon.co.uk Associate's Programme. Basically, by clicking on the image each time you shop with Amazon, 5% of the cost of your purchase will automatically be transferred to the TPA Charity Bank Account.

This will take you directly to Amazon UK where you can purchase anything as you would normally. During 2010, we will be working toward making even greater strides in our campaigning to get a better diagnostic and treatment protocol within the NHS. A great deal of work is going on behind the scenes and we will try to keep you up to date with events.

If you wish to support TPA in this way, please bookmark this page and use it for **ANY future Amazon UK purchases** - books, CDs, electronics, etc. Pass the link also onto your family and friends and ask them to use it too.

IMPORTANT:

Please be aware that doctors can prescribe unlicensed medicines and they can use other guidelines for the diagnosis and treatment of hypothyroidism – Even if those guidelines were written and published in another country

If your GP/Endocrinologist is refusing to give you a choice of treatment or s/he is strictly following the British Thyroid Association guidelines on the diagnosis and treatment of hypothyroidism, and if s/he says they are unable to treat outside of their guidelines, **then take a copy of the latest information (April 2009) from the Department of Health, written by Ann Keen MP, Parliamentary Under Secretary of State** which she has sent out to everybody who wrote to her with queries regarding concerns about the above guidance and other hypothyroid concerns). In the standard letter, she states:

"Doctors are encouraged not to rely too heavily on the results of blood tests, but to use their clinical knowledge and an assessment of the symptoms experienced by individual patients in making a diagnosis for thyroid treatment. Doctors are free to use whatever guidance they feel is appropriate

when making a diagnosis. This includes guidance published in other countries.
. . . I should add that under their terms of service, GPs are allowed to prescribe any product, including any unlicensed product or product not licensed for a particular indication that they consider to be a medicine necessary for the treatment of their patients under the NHS, subject to two provisos. These are that:

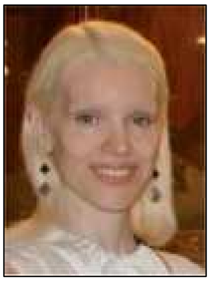
- *the product is not included in Schedules 1 or 2 of the NHS General Medical Services Contracts (Prescription of Drugs etc) Regulations 2004, otherwise known as the Selected List Scheme; and*

- *GP's are prepared to justify any challenges to their prescribing by the Primary Care Trust.*

It is the responsibility of health professionals to decide on the most appropriate treatment for their patients. If a person has any concerns over their treatment or the drugs they are prescribed, they need to raise these concerns with their GP or consultant.

Nutritional Supplementation for Improving Thyroid Function

By Dr Theodora Mantzourani, MD, BSc, MRCGP, WOSAAM



Thyroid hormones impact on cellular DNA to increase the production rate of cellular ion pumps (i.e., sodium/potassium ATPase) and mitochondrial combustion chamber elements so that cells can trap the energy they need to perform the work of living. For this reason, both ECG voltages and basal temperatures in hypothyroidism tend to be low. Many thyroid problems are made worse by specific vitamin and mineral deficiencies that hinder the conversion of raw fuels (protein, fat and carbohydrates) into energy. Therefore, common signs of hypothyroidism, like cold intolerance and weight gain are worsened by nutritional deficiencies.

Nutritional supplements can help prevent or rectify deficiencies and thus improve thyroid function by affecting all stages of thyroid hormonal function: T4 manufacture, T4 to T3 conversion, T3 binding to intracellular receptors.

Here are some considerations for nutritional supplementation which may improve thyroid function:

- Zinc, vitamin E, vitamin A, B2, B3 and B6 are all involved in the synthesis of thyroid hormone.

- Zinc is a cofactor in one of the deiodinases that converts T4 to T3 and zinc deficiencies can prevent the proper activation of DNA programmes (zinc finger malfunction).

- Low zinc is commonly encountered in the elderly especially in the institutionalized ones and as we know the incidence of hypothyroidism increases with age.

- Vitamin A is essential for the formation of intracellular receptors for T3.An evaluation of vitamin A status should be considered in patients with hypothyroidism as decreased thyroid hormone levels can impair the conversion of beta-carotene to vitamin A.

- Selenium, a cofactor in another deiodinase is estimated to be significantly deficient in most diets worldwide. Selenium has been shown to decrease thyroid antibody levels in autoimmune thyroid conditions such as Hashimoto’s, which is thought to account for a big percentage of subclinical hypothyroidism. Human populations have developed Keshan disease and hypothyroid cretinism when they have become simultaneously deficient in selenium and iodine.

- Adequate dietary iodine supply is essential for proper thyroid function (T4 and T3 synthesis). Patients with hypothyroidism should be evaluated for low iodine status especially as the use of iodinated salt has decreased and even when used its bio availability is low(10%).There is an increasing number of iodine deficient cases now days due to low salt intake, the presence of goitrogens (soy),chemical exposures to bromine (bakery products, brominated vegetable oils, Gatorade and other soft drinks)),fluoride, chlorine, declining mineral levels in soil etc. Iodine supplementation should occur only when deficiency has been proven and under medical supervision. Iodine deficiency can be aggravated by deficiencies of vitamin A, iron and selenium.

- Antioxidant supplementation may be very important when environmental toxins are a major contributing factor. Supplementation with vitamins C, E and *Curcuma longa* (turmeric) has been demonstrated to improve thyroid function in rats with methimazole-induced hypothyroidism. The higher the metabolic rate, the greater the oxidative stress. In patients with hyperthyroidism, supplementation with antioxidants such as lipoic acid and N-acetylcysteine as well as coQ10 and B vitamins should be considered. Interestingly, there are animal experiments indicating oxidative stress in hypothyroidism as well with vitamin E and taurine displaying protective effects.
- L-carnitine may play a role in the muscular weakness common in both hyper- and hypo thyroidism; carnitine modulates thyroid hormone action in the periphery inhibiting both T3 and T4 entry into the cell nuclei so normalizing this nutritional factor can improve symptoms in hyperthyroid patients.

  Collectively, the effects summarized here demonstrate the potential for improving thyroid hormone function by normalizing and optimizing nutritional factors that impact on cellular responses.\

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The UK new Coalition Government is asking for help - and TPA can give it to them

Our new Coalition Government has issued a warning on the UK's 'staggering' debt in preparation for the budget on 22nd June 2010. This government has been warned that the UK faced a "formidable" challenge to repair its battered public finances. The deficit in question is already in excess of £150 billion – currently forecast to hit £163 billion this year. This has ballooned to nearly twice the size of the shortfalls seen during previous economic downturns in the 1970s and early 1990s.

This Coalition Government has invited people throughout the UK to write to them with any ideas that might help save several millions of pounds.

I am writing to suggest how they could save many millions of pounds if only the Department of Health would actually listen to the horror stories of tens of thousands of UK citizens who are being left to suffer so unnecessarily with the symptoms of hypothyroidism, and all because of the seriously flawed 'Guidance on the Diagnosis and Management of Primary Hypothyroidism' created by the Royal College of Physicians (RCP), the British Thyroid Association (BTA) et al. There are over a QUARTER OF A MILLION sufferers, in the UK alone, who are being refused a diagnosis because the BTA, RCP et al tell doctors they must not diagnose hypothyroidism if their patients' serum Thyroid Stimulating Hormone (TSH) result is within the reference range laid down by them of 0.5 to 10.0, a reference range so wide as to be unmatched by every other country on the globe. In America, the range is 0.3 to 3.0. In Germany, Belgium and Sweden, it is 0.3 to 2.5, with a recommendation in Belgium that the upper level be dropped even further to 1.5.

In consequence, sufferers are being denied a proper diagnosis, and appropriate medication (i.e. thyroid hormone replacement) that would give them back their optimal health. For those who are diagnosed, the RCP, BTA et al tell doctors they must treat this condition with levothyroxine (T4) ONLY and that triiodothyronine (T3), whether synthetic or natural, should not be prescribed. Many sufferers, for many and varied reasons, do not convert the mainly inactive prohormone T4 into the active hormone T3. It is T3 that every cell in the body and brain needs to make them function. So these are the people, who, through worsening ill health, are being forced to leave paid employment and live on State Benefits. Those patients correctly diagnosed and treated no longer have to depend on State Benefits, having been able to return to work - thus adding to the Nations wealth.

Instead, they are being prescribed selective serotonin reuptake inhibitors (SSRIs) antidepressants and many and varied prescriptions for their remaining individual symptoms, quite unnecessarily.

Whilst taking into account the costs of these medications, consideration must also be given to the massive cost to the NHS and also, the cost of other medicines prescribed when T4 alone does not fully resolve the patients' symptoms. Those patients who still exhibit symptoms when on T4 only, are told they are suffering from a functional somatoform disorder (meaning, it's all in your head) or they have non-specific symptoms, and no further investigation is carried out.

There are two papers that stand out as demonstrations of the limits of the protocol for diagnosis and treatment of thyroid hormone deficiencies. First, Drs Baisier, Hertoghe, and Eeckhaut (*Thyroid Insufficiency? Is Thyroxine the Only Valuable Drug?*) studied the failures of these protocols within endocrinology and found that these subjects had the same collection of symptoms as patients with deficient thyroid gland secretion. They found an evaluation of eight *nonspecific symptoms* is a good clinical diagnostic. They also found diagnostic information in the subjects' urine that correlated better with the symptoms. And finally, in a follow-up study, they treated these failed subjects with desiccated thyroid, (containing T4 and T3), successfully.

Second, Dr. Marshall Goldberg, discovered euthyroid hypometabolism in 6% of his 500 subjects. They had the list of symptoms of hypothyroidism but were not found to have any deficiency of the secretion by the thyroid gland. Thus, Dr. Goldberg explained the existence of symptoms in spite of a thyroid gland function test, within reference ranges. These patients were treated with T3 successfully. These studies have been available for over 40 years, yet the RCP, BTA et al. has chosen to ignore them - leaving such patients to continue suffering unnecessarily.

Those suffering the symptoms of hypothyroid chronically use more prescription drugs, especially for diabetes, cardiovascular disease and gastrointestinal conditions. Again, these add a great financial strain on the NHS and an overwhelming burden to the quality of life of the quarter of a million sufferers in the UK alone.

Most patients being denied a proper diagnosis are prescribed antidepressants. I know this, because we have now 1710 members of TPA and the majority have confirmed this to be the case. Irving Kirsch's recent study, which took place at the Department of Psychology, University of Hull (25 February 2008) is the first to examine both published and unpublished evidence of the effectiveness of SSRIs, which account for 16 million NHS prescriptions a year. The largest study of its kind concluded that antidepressant drugs do not work. **More than £291 million was spent on antidepressants in 2006, including nearly £120 million on SSRIs.**

Depression has an association with lower thyroid hormone levels and research has shown that improvement can be achieved with thyroid hormone replacement. There is an association with anxiety and lower thyroid hormone levels and again, research has shown improvement with thyroid treatment replacement therapy.

Memory loss and Alzheimer's disease likewise have an association with lower thyroid hormone levels. Both these conditions have shown improvement with thyroid treatment.

This is just a small part of what I will put forward to Andrew Lansley MP, but it would help our cause CONSIDERABLY if you would also play your part and write a letter to **Andrew Lansley MP, Secretary of State for Health, House of Commons, London SW1A 0AA** - setting out your experience within the NHS and asking that this whole diagnostic and treatment protocol for those suffering the symptoms of hypothyroidism be investigated. Not doing so, will continue to cost the NHS millions of pounds.

ALWAYS stress the pernicious involvement of the RCP, BTA et al. as to the serious harm they cause through their many misleading and often incorrect statements, e.g. "*the British Thyroid Association recommend the use of sensitive and specific blood tests as the only method for the precise diagnosis of thyroid dysfunction and for the monitoring of treatment with approved medications*" and also . . . *"Overwhelming evidence supports the use of Thyroxine (T4) alone in the treatment of hypothyroidism. We do not recommend the prescribing of additional Tri-iodothyronine (T3) in any presently available formulation, including Armour thyroid, as it is inconsistent with normal physiology, has not been scientifically proven to be of any benefit to patients, and may be harmful."*

None of these statements have been backed up by reference to relevant scientific studies. TPA, in refuting their claims, has adduced hundreds of references to which the attention of the RCP, BTA et al. have been drawn, without ever having received acknowledgement, apart from the President of the RCP asserting that they will not be entering into any further correspondence regarding this matter.

How outrageous is that?

Andrew Lansley has the power to put an end to this appalling situation. If there are enough of us who are determined to end this depravity once and for all, we can, and will, succeed. Please help us to do this.

TPA Member Success Stories

Sue's story

I went to my GP in October 2008 complaining of palpitations (missed beats and strong beats). The GP said it was normal but would do a blood test (TSH). The test was normal (sic) but he then did an ECG which showed ectopic beats. I also became breathless at about this time. I was put on beta blockers (for the palpitations) and was told that I was hyperventilating and was not therefore "breathless". By this time I had fatigue and pain in my fingers, wrists, forearms, shoulders and thighs. I was referred to a cardiologist (who said there was nothing wrong) and a rheumatologist (who said I had early-stage fibromyalgia). He referred me to Occupational Therapy (to learn how to cope with the pain) and Physiotherapy (because I might have become de-conditioned).

I returned to my GP who said I was overweight and depressed. At this point I got scared and Googled "why am I so tired all the time, and hit upon TPA, STTM and TUK. I self-diagnosed adrenal fatigue (via Comprehensive Adrenal Stress Profile from Genova) and hypothyroid (by signs and symptoms), and treated firstly with glandulars. I saw some improvement, but kept relapsing. Then I trialled HC (excellent results) and NDT (less good). At this point I consulted Dr P and have continued to improve under his supervision and fine-tuning. I have tissue resistance and conversion problems, so am on T3 and HC, with promising results. I am working full-time and the breathlessness has gone since upping the T3. Had I submitted to the NHS I would be on a graded exercise programme, living with pain and on anti-depressants. I have not been back to my GP, but will do so when I am fully well. I have a friend who has very similar symptoms to me who is under the "care" of an endo. She is more or less house-bound now (tests are "normal) and not working. I consider myself to have had a lucky escape, thanks to the support and sensible, well-researched help found on TPA. **— Sue Ramsey**

Carol's story

I was diagnosed with a goiter of my thyroid gland in 1990 and was monitored on the NHS Thyroid Register annually – received no treatment whatsoever as my blood panel was 'normal' this continued for 12 years during which time my goiter got bigger and bigger. I made the decision that me and it had to part company.

My complete thyroidectomy operation was carried in September 2002 and was placed on Levothyroxine immediately, took 2 years to stabilise my dosage. During the 7 years of being on Levothyroxine I had really bad aches and pains especially my knees and feet, brain fog, depression, anxiety, HORRENDOUS weight gain despite careful calorie control and as much exercise I could do with the pains in my joints, I felt as though I was an old woman instead of being in my 40's. Due to my bad health after my operation I lost my very well paid job as I just couldn't handle it anymore. My health had completely dropped to bits – my life was shattered.

I visited my doctor several times, each time got told that that was it and 'just get on with your life' what life? I felt as though the door had slammed in my face.

We moved out here to Thailand back in 2006 and since than I have had to take my health into my own hands and after doing a lot of research found out about Natural Desiccated Thyroid (NDT). I have been taking NDT since January 2010 and so far my life has improved tremendously – to date having lost 37lbs of my gained bulk, the pains have completely gone out of my joints and now I am 'a young 54 year old' I will never, never ever go back to Levothyroxine while ever there is breath in my body.

I know that if it wasn't for you and the TPA I would still be on LevoT hobbling around like a very old woman in terrible pain and not really having a life - it is through your site that I now have my life back - THANK YOU

I grant you permission to use my story together with my name – Mrs Carol L Kaczor, Thailand

Moira's Story

I have severe congenital hypothyroidism and take 200-225 mcgs daily. It is a very unpleasant and time consuming condition which I have been trying to manage for over twenty years. It would have helped if my doctors had taught me how to live and manage this condition. I was never told how to take this medication, never told to take it on an empty stomach. When I was just 9 years old, I was taking as much as 300 mcgs daily and this made me severely hyperactive.

Now that I am older, I have learned through bitter experiences, how to take this drug responsibly. No thanks to my GPs who, in my opinion, have been useless in helping me. I am now going to go on a sick note and will end up on welfare benefits probably for the rest of my life because I have grown up on this drug and it has failed to give me the quality of life that I was told that I could expect. Doctors are liars and murderers who can potentially ruin your life like mine has been. They never told me about the side effects, they never told me anything about the stress my liver would be on and what kind of diet I should follow. I used to complain about the side effect but they made me feel like it was all in my head and now that I am older I am totally disgusted at the level of care and treatment that I received.

I sometimes wish that I would have been better off dead than to have lived the way I have lived for the last twenty years. It has been very difficult for me to lead a normal life because I totally rely on levothyroxine and it initiated my physical and psychological development which has had too many complications. I sometimes wish to stop treatment but have no choice but to live on.

I think the NHS can not afford to deal with hypometabolic disorders responsibly. I was a cretin, mentally retarded, then they suddenly pumped me full of levothyroxine and I metamorphosed into a 'normal' looking human being who was completely unprepared for the changes that should have been introduced to me gradually. I should have been rehabilitated and counselled and socialized back into life which never happened. I was given my medication, and told to shut up and take it. I am one upset individual who has had his life ruined by incompetent fools who earn large sums of money for screwing people up sat on their backside drinking tea and just getting through the week pumping people with drugs and lies.

I am lucky because I educated myself to deal with the complex socio-psycho-physiological challenges that this condition presents. But not everyone is like me.

Jane's story

I was diagnosed quickly as I refused the anti depressants... my dose got increased quickly... bloods got in that bloody normal range and then the fight began.... kept saying thought I needed t3 .... doc told me I wasn't American!!!!... also told me 'man at the lab says i was ok'!!!!!... fought and fought (and cried.... A LOT) eventually saw an endo whom I persuaded (with a machine gun to his head) to give me t3.... instant turn around... feel sooooo well now!!... back to the gym etc.... I was in slimming magazine this time last year as I had lost 4.5 stone... I put 5 stone on in 3 months despite following the diet!!!.... I have just started to lose it these last 2 weeks!!!!.... and guess what... they now want to reduce my dose (via the endo’s secretary over the phone!!!... told her to tell him I had to see him for that and that he better put his boxing gloves on!!!!!... I would not have thought I could ever feel well again.... but I do... I am all but normal once again... funny... the doctors phone me now.... as the lab results could suggest over prescribing.... they couldn’t have cared less when I was sat in reception bawling my eyes out.... cos then it was all in my head!!!!! Anyhow... whoever ends up in the papers lets hope it makes some doctors listen.... you meet so many people on the net who are suffering... it has to stop!!!! Take care Jane xx

Penny’s story

In April 2004 we returned from our holidays. I was prepared to be jet-lagged for a few days after all it's a price worth paying. After a week though I wasn't feeling any better and as the following weeks dragged on I just felt worse....

After 4 or 5 weeks I finally went to see my GP. I had crushing pains in my legs, especially at night and I was exhausted all the time. From being a very active, healthy woman, I had become a shadow of myself almost overnight.

The GP said it was a virus and that it would pass and sent me on my way.

In October of that year I started to have a very erratic heartbeat, to the point that I actually fainted on a couple of occasions. The second time I was really alarmed so I went to the local AandE. They did tests and discovered I had an elevated TSH. I was started on 50mcg of thyroxine immediately and a letter was sent to my doctor.

Over the following months, and years, my dose was steadily increased until today I am on 150mcg.

Nevertheless, the symptoms didn't go away. They actually worsened. The pains spread all over my body (I've described it as feeling as though my blood was toxic - sounds dramatic but that's the best description I can give). The occasional periods of exhaustion became a regular occurrence, with times of bone crushing tiredness and whole body weakness...unable to lift a cup or get my head off the pillow in the morning. (To which one doctor said "...we all get mornings where we don't feel like getting up"). I developed "brain fog" to the point where I constantly lost my way in mid-sentence or forgot the names of friends and colleagues.

My weight began to fluctuate, so that I now have clothes in three different sizes. I began waking through the night, despite being exhausted. My eyes became dry and watery and "puffy" much of the time. Then I started to lose my eyelashes. My skin became dry and itchy, at first just my hands, but later all over my legs and back too. I developed strange orange patches in the creases of my skin. My periods stopped. My hair grew thin and lifeless.... I was too exhausted and weak to have time for family or friends and without a diagnosis my job, which I loved, was increasingly at risk.

I saw various GPs over this time - it's a multi GP practice - who couldn't really suggest anything apart from asking "whether I was depressed?" Of course I was! Wouldn't anyone be fed up if they constantly felt so ill.

From my point of view, dismissing me, and my symptoms, as being some menopausal, neurotic episode did nothing to help find the problem. Increasingly it looked like an easy get out.

Finally, one of the GPs referred me to a general consultant. He arranged for me to have a fine needle aspiration test. However, when I got there the doctor took one look at the ultra-sound image of my thyroid and said there was no point in proceeding as my thyroid had wasted away to the point where it looked like "...a lump of wood" and had ceased functioning.

On returning to the consultant (with my husband in support because by that point I was incapable of taking much in) he told me that I had Hashimoto's, probably as a consequence of an auto-immune response to the virus I'd contracted in 2004. He concluded by saying, "Don't take this as a diagnosis but...there's also the possibility that something could be going on with your adrenals." I asked him how that could be treated. He said it couldn't. He referred me to a rheumatologist for the pain and prescribed progesterone.

By this point I was becoming increasingly disillusioned and started to realise that I was going to have to start helping myself as clearly the medical profession wasn't going to.

Thankfully, in so many ways, I found the TPA website. As I read the pages, I actually cried. For the first time I realised I wasn't alone.

I digested every word, read references and files and joined the forum. At last I felt I had the means to get better and get my life back and I made a conscious decision to do everything I could to recover....with or without the help of the medical profession.

One evening, however, I was even more poorly than usual. My husband found me curled up on the bed. The pain was mind numbing and the terrible tiredness left me too weak to even lift my head. He immediately phoned the GP who arranged for me to go into the surgery the following morning.

Ever the optimist, I managed to make it to the surgery, where the doctor commented that "...until the thyroid problem had started, they hadn't really seen much of me at the surgery." She then announced that I now had CFS. I asked how depression or CFS could be causing my skin problems. She said they were unrelated and prescribed cortisone cream. I asked her how it could account for my dry, puffy eyelids. She told me that was also unrelated. I asked her about the pains. She said I was going to see a rheumatologist. She told me that the only way to deal with my exhaustion was to "work through. Then she prescribed anti-depressants.

When I got home, I shredded the prescription.

Two weeks ago, I stopped the levothyroxine and started taking NAE to boost my adrenals. Last weekend, I had three of my grandchildren to stay over, attended a 40th birthday party until late at night. My periods returned. I cut the grass. I'm sleeping through the night and waking refreshed in the morning. I'm working, and delivering, at almost the level I was before this nightmare started. I've just come back from a very pleasant bike ride. Even though I still have the pains and occasional tired spells, I'm getting me back.

I've just sent off for a supply of Armour thyroid and once I've given my adrenals the chance to recover I will self-medicate with that. I've found it quite scary to turn away from a medical profession in whom I've always placed my trust, but now I feel that I will get better despite the current medical protocol and not because of it.

I will tell my GP exactly what I'm doing, and I hope she will support me. I am not prepared to give up on life and simply fade away as I fear so many other sufferers must be doing on NHS treatment.

Barbara H's story

It's only through being a member of this group that I have read up on fibromyalgia.

Last summer I was incredibly ill after my GP reduced by thyroxine dose by two thirds overnight (and over the phone!) and I literally had to beg for a referral to an endocrinologist who I hoped would sort me out (my begging for a referral was initially ignored and I was told it would get sorted "naturally in three to four months" (!) until I uttered that magical four-lettered word B.U.P.A)

At the time I mentioned to the endocrinologist about excrutiating leg pain which I suffer, particularly in the evening when I get tired, which has, in the past, reduced me to tears. He pooh-poohed the notion there could be anything connected to my hashimoto's and signed me back to my GP with the diagnosis that my thyroid blip had been due to stress.

I am so annoyed as, having read up on fibromyalgia, it now sounds like the symptoms may be related to that, if/and not directly related to my thyroid issues.

It's especially worrying as the doctor who ignored my pleas was meant to be a "good" endocrinologist.

I'm so thankful I found this group, and can't thank Sheila, Lilian and the others enough for all their support. Goodness knows where I'd be without it!

Just some of the stories written by members – and there are thousands more.
If you have not sent in your own story, please do so.
Send to sheilaturner@tpa-uk.org.uk

So why do the GMC, the RCP and the BTA et al continue in their refusal to listen?

Local Thyroid Patient Advocacy Support Groups forming

Local Thyroid Patient Advocacy (TPA) support groups are now forming. If you are interested in starting one in your area, contact Sheila at **sheilaturner@tpa-uk.org.uk** with your name, address, telephone number and email address so your group can be published in future newsletters and on the TPA forum.

Are you an enterprising business person or hobbyist who would like to advertise your products or services?

If you're a TPA member, you can advertise in these newsletter pages at no cost. Contact Sheila at **sheilaturner@tpa-uk.org.uk** or Lee at **lee@leeappleyarddesigns.com** with your ad ideas.