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BTF News

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Happy New Year to all our supporters

DIAGNOSIS AND TREATMENT OF HYPOTHYROIDISM – JOINT STATEMENT

Many people are not surprisingly confused because of what they see in the media and on the internet about treating hypothyroidism. And many endocrinologists have expressed concerns that some patients both with and without thyroid disease are being inappropriately diagnosed and managed, using thyroxine (T4) and other thyroid hormones in ways that compromise patient safety.

In response to these concerns, the Royal College of Physicians (in particular the RCP Patient and Carer Network and the Joint Specialty Committee for Endocrinology & Diabetes), jointly with The Association for Clinical Biochemistry, The Society for Endocrinology, The British Thyroid Association, The British Thyroid Foundation Patient Support Group and The British Society of Paediatric Endocrinology and Diabetes, have now issued a joint statement about the diagnosis and treatment of primary hypothyroidism. The statement is also endorsed by the Royal College of General Practitioners.

'This is potentially an enormous problem, given that in any one year one in four of the population has their thyroid function checked' says the statement.

Among its recommendations are, that patients with primary hypothyroidism should be treated with T4 alone, and that T4 or other preparations containing thyroid hormones should not be prescribed to patients with thyroid blood tests within the reference ranges. It states that it does not support the use of thyroid extracts or thyroxine and triiodothyronine (T3) combinations without further validated research published in peer-reviewed journals.

It does not, however, completely exclude the use of T3 in the treatment of hypothyroidism by accredited endocrinologists in individual patients.

'Patient safety and well-being are crucial. This statement clarifies the current situation based on scientific evidence, but at the same time keeps the door open for future research to further help people with hypothyroidism' said Janis Hickey, BTF Director.

The statement appears in full on page 5 of this issue.

IN THIS ISSUE....

BTF INFORMATION EXCHANGE WEEKEND

The White Hart Hotel, Harrogate, was the venue for a BTF information exchange weekend for volunteer local support group co-ordinators and telephone contacts on 29th and 30th November. Sue Sherwood, one of BTF's telephone contacts, reports as follows:

Until this Information Exchange Weekend I had only had telephone contact with other BTF volunteers and co-ordinators, so it was really interesting to be able to put faces to the names at last.
(continued on page 2)

Pictured above at the BTF Information Exchange weekend, from left to right back row: Angela Hammond, Janet Prentice, Sandra Brownlee, Jane Betts, Sue Sherwood, Janis Hickey (BTF Director), Paul Morgan, Lesley Lovell and Peter Foley. Front row: Sue Hume, Christine Hacon, Carole Ingham and Christine Kelly.

(continued from page 1)

On Saturday we listened to speakers on various topics such as Angela Jones (Harrogate Council for Voluntary Services - CVS), who informed us of the support we could receive from our own local CVS, and Carole Ingham (BTF local co-ordinator, Bolton) who spoke to us about all the help and support and training she had gained from her local CVS.

Pictured above, from left: BTF local group co-ordinator for Bolton, Carole Ingham with speaker Angela Jones, Harrogate CVS.

Maureen Ryan, an independent trainer, joined us in the afternoon and spoke about telephone listening skills, counselling and motivation. Some topics were very interesting and everything was relevant to the issues we face as telephone contacts and local co-ordinators.

On the Sunday, we were joined by BTF Trustee Miss Alison Waghorn, who is an endocrine surgeon, and former BTF Trustee Dr Peter Hammond, who is a consultant endocrinologist. They both kindly gave up their Sunday morning to speak to us about the patient treatment pathways of different thyroid disorders including hypothyroidism, hyperthyroidism and thyroid cancers. This section ran over its allotted time, but this did not matter to us at all because everything was so very interesting.

As well as meeting up with the other volunteers within the BTF who are telephone contacts or run local groups, it was also good to meet others who had experienced the same medical symptoms and treatments and many views and opinions were exchanged.

The hotel was lovely and we were all treated like VIPs. In all it was a very enjoyable and productive weekend.

We would like to thank the Society for Endocrinology and the Roger and Jean Jefcoate Trust who co-funded the Information Exchange Weekend.

Pictured above: Endocrine surgeon, BTF Trustee and speaker at the Information Exchange Weekend, Miss Alison Waghorn.

Pictured above: Endocrinologist and past Trustee of the BTF and speaker at the Information Exchange Weekend, Dr Peter Hammond.

28-DAY PRESCRIBING – THE RESPONSE FROM THE DEPARTMENT OF HEALTH

Following our survey into prescribing practices (see the article by Professor Simon Pearce: 'Your thoughts about 28-day levothyroxine prescribing: - results of the BTF survey' in ***BTF News***, issue 65, Summer 2008) BTF Director Janis Hickey wrote to the Health Secretary requesting a review of the present policies, which mean that in practice, many GPs are prescribing levothyroxine for only 28 days. She pointed out that those patients with a life-long dependency on medication such as levothyroxine are in a different category from patients receiving short-term care, and that the vast majority of hypothyroid patients have an annual blood test and remain on a fixed dose from one year to the next. She also pointed out that increasing a one- or two-month supply to three months could save an estimated than £6.5 million a year in dispensing fees as well as saving doctors' and pharmacists' time.

The Department of Health (DoH) wrote back declining to take up the issue, stating that there has been no Government directive on the length of prescriptions. We are reproducing the DoH letter in full on the opposite page:

This is disappointing for members who have written to tell us about the inconvenience of collecting the prescription or having it dispensed monthly having a negative impact on their lives, particularly people who worked long hours or shift work, people living in rural areas, the elderly, and those with physical disabilities. It is also awkward for people taking long holidays, or who travel frequently for their work. Some people had run out of supplies because they weren't able to refill their prescription on time; others found the process a constant reminder that they had a health condition.

BTF has written to its local MP and will be discussing whether further actions are appropriate with other patient associations with members with chronic conditions. In the meantime, we recommend that BTF members who have been refused a prescription for levothyroxine for longer than 28 days take up the matter themselves, by:

- asking your local MP to take up the matter, and

- giving your GP a copy of the DoH letter, pointing out that there has been no Government directive, that the length of prescription is up to the prescriber, and that the DoH recognises that longer prescriptions are more appropriate and convenient for some patients as stated in the guidance from the National Prescribing Centre.

Please write and tell us of your experiences.

YOUR EXPERIENCE OF SERVICES FOR THYROID EYE DISEASE: KEY FINDINGS OF THE TEDct/BTF SURVEY

Many thanks to all of you who have recently completed the questionnaire survey for the Thyroid Eye Disease Charitable Trust (TEDct) and the British Thyroid Foundation on your experience of services for treatment of your thyroid eye disease. In total, 395 of you from all the regions of the United Kingdom have

10 October 2008

Dear Mrs Hickey,

Thank you for your letter of 1 October to Alan Johnson about the length of prescriptions. Mr Johnson receives a large volume of correspondence and unfortunately he is not always able to respond personally. Your letter has therefore been passed to me for reply.

While it may be common practice nowadays for prescriptions to be issued only for one month, or 28 days at a time, there has been no Government directive to specify the length of time for which prescriptions should be issued. **Responsibility for prescribing, including the issue of repeat prescribing and the length of prescriptions, rests with the prescriber who has clinical responsibility for that particular aspect of a patient's care.** It is the responsibility of the local Primary Trust to ensure that adequate controls are in place, and they may also issue advice to prescribers on repeat prescribing mechanisms, including the length of time for which prescriptions are issued.

The issuing of prescriptions for shorter periods of time commonly arises from attempts to cut down on the amount of medicines wasted each year. For instance, if the prescriber decides to change the patient's medication (for example because the patient is suffering from side effects) the unused medicine cannot be reissued to another patient. Returned medicines are destroyed because there is no guarantee that the medicine was kept under the right conditions, or has not been contaminated. Issuing shorter prescriptions also gives the prescriber the opportunity to review ongoing medication, which is important for some groups of patients. In addition, there may be safety considerations associated with storing large quantities of a particular drug in the home, and some medicines have a short shelf life.

However, the Department recognises that prescriptions for longer periods of time are more appropriate and more convenient for some patients who may wish to discuss this with their GP. The National Prescribing Centre issued some guidance in 2000 to Health Authority and Primary Care prescribing advisers. This outlines advice on what factors should be taken into account when considering prescription duration.

I hope this clarifies the Government position.

Yours sincerely,
Lynsey Morton
Customer Service Centre
Department of Health

responded – one of the largest surveys on this subject ever conducted. We are still in the process of analysing the complete survey, but we would like to share with you a summary of key findings that the analysis has shown so far.

(a) Majority of respondents were female (91%), and above the age of 45 years (74%)

(b) 41% of respondents had TED for over 10 years, 27% for 5-10 years, 31% for 1-5 years, and 1% for less than 1 year

(c) For 45% of respondents, it took more than 6 months from the first symptoms to the correct diagnosis of TED

(d) 15% and 20% of respondents were given allergy and conjunctivitis, respectively, as the initial diagnosis for the eye condition

(e) Majority of respondents (75%) initially consulted GP for first symptoms of TED

(f) 71% and 41% of respondents had a history of double vision and decreased vision, respectively, due to TED

(g) Respondents attended various combinations of endocrinology, eye or specialist TED clinics for the treatment of TED

(h) Overall, only 25% of respondents attended a specialist TED clinic; of these, 33% waited 6 months or more from the first consultation with a doctor to being seen at a specialist TED clinic

(i) 60% of respondents felt they had been offered help to cope with the physical aspects of the disease, but only 27% agreed they had been helped to deal with the psychological impact

(j) Only 56% respondents were satisfied with the overall treatment they received for TED; more respondents who had attended a specialist TED clinic were satisfied with the treatment than those who had not attended a specialist clinic (67% versus 52%).

These results suggest to us that we need to do much more to ensure that patients with TED are seen early, that their disease is correctly diagnosed, and that they are referred promptly to specialist clinics where they receive both psychological and medical support. We would be interested to hear any comments from readers on these results.

THYROID MEDICATION SURVEY – UPDATE

Thanks to all of you who responded to our thyroid medication survey which was circulated with the *BTF News* Summer 2008 issue (No. 66). We received over 1000 responses. We will soon be analysing the data and hope to report on progress in the next issue.

GOVERNMENT LIFTS BAN ON TOP-UP TREATMENT

As reported widely in the Press in November, the Government has lifted its ban on top-up treatment. Patients who want to use drugs that are not available through the NHS are now to be allowed to pay for them privately without losing their entitlement to NHS care.

Until recently, patients who wanted to pay for drugs that the NHS doesn't provide had to get their entire course of treatment privately, putting such treatments out of the reach of many.

This move is part of a package of reforms laid out in the Richards Review.

The Review, entitled *Improving Access to Medicines for NHS Patients*, laid out 14 key recommendations to the Department of Health. The Health Minister, Alan Johnson, accepted all 14 of the recommendations. The Review was led by Professor Mike Richards CBE.

For thyroid patients, perhaps the most significant consequence is that thyroid cancer patients who are not able to obtain Thyrogen ® through their NHS Trust will now, should they wish to, be able to pay for it.

IODINE CONTENT IN SALT

An Editorial in the medical journal *The Lancet* about a recent UNICEF report on its progress towards the worldwide elimination of iodine deficiency prompted a letter from Professor John Lazarus (Cardiff University School of Medicine and BTF Trustee) and Dr Peter Smyth (University College, Dublin).

They expressed their concerns that while household use of iodised salt has increased from 20% to 70% in developing countries, Europe still lags behind and the UK and Ireland are 'at the bottom of the international league table' in terms of the availability of iodised salt. They warn that 'up to 50% of pregnant women could be significantly iodine deficient during gestation' according to data collected from NE England, Scotland and Wales, with a similar pattern of iodine deficiency in Ireland.

The authors measured the iodine content in 36 different salt preparations obtained from nine major national supermarkets in Cardiff. Only four samples contained measurable quantities of iodine, and of these, only two contained meaningful concentrations related to preventing iodine deficiency.

The letter is published in the September 13th 2008 issue of the journal. The authors, who are respectively the UK and Ireland representatives of the International Council for Control of Iodine Deficiency Disorders (ICCIDD), suggest that '… the situation relating to iodine consumption, particularly in pregnancy, be systematically examined in both countries'.

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Editorial, Iodine deficiency—way to go yet. *Lancet* 2008; 372: 88.

For the UNICEF report to which the Lancet Editorial refers see:
http://www.unicef.org/publications/files/Sustainable_Elimination_of_Iodine_Deficiency.pdf

HYPOTHYROIDISM AND DEPRESSION

In the Summer 2008 edition of the *BTF News* No 65, we published a request for help from Sam Kirby for a research project entitled 'hypothyroidism and depression'. Sam has recently written to us to say that a very high number of our members contacted her and she would like to express her grateful thanks to all those who got in touch with her. Her study is qualitative and therefore she has only been able to include a small number of people but she is nevertheless appreciative of all the support she has received.

FAREWELL TO…

Dr Peter Hammond, Mr Mike Gourlay and Mrs Wilma Beckett who are stepping down after many years as Trustees of the BTF. We send our grateful thanks to them all for their contributions over their years of service.

CARDIFF DOCTORS GET ON THEIR BIKES

Traditionally a time for hitting the gym to make up for the excesses of the Christmas period, this New Year sees three Cardiff doctors working out harder than most as they prepare for a gruelling 350 mile cycle ride around Wales.

Professor Aled Phillips, Dr Kieron Donovan and Dr Steve Riley – all consultant nephrologists at the School of Medicine in Cardiff – have been spending their weekends on their bikes in preparation for a major fundraising effort to raise £50,000 for the Kidney Wales Foundation. Their epic journey, which will see them visit every dialysis unit in Wales, begins on 6 March and the finish has been timed to coincide with World Kidney Day (12 March).

Donations to support the trio can be made at their secure online donation site at http://www.justgiving.com/ckdwales

DONATIONS

Many thanks for your generous donations - we are grateful for them all. Remember to contact us if you are undertaking a fund-raising event in aid of BTF, giving plenty of notice if you require a 'BTF' T-shirt or running vest, and please send us a photograph for our records and possible inclusion in the newsletter. Also, check with your employer if you are undertaking a fund-raising event, as some employers operate a match-funding scheme in which they match all or part of any funds you raise.

We would also like to express our gratitude to the following people:

MWH, Llanishen who raised £111 through their staff holding 'dress down' days.

Mrs B Dobbs and members of the Embankment Golf Club Wellingborough who raised £207 during her year as Lady Captain.

Hanson Reunion 1957 for the donation of £114.13.

Aileen Collins who completed this year's Great North Run in 1hr 58mins (a personal best) and raised over £500 in aid of BTF. Congratulations Aileen!

Pictured above: Aileen Collins who completed this year's Great North Run in aid of BTF.

Eastlands Homes Community Safety Team, Emmet Hynes and Manchester Radio On-Line who stayed overnight in a 'haunted' building and raised £504 for BTF. Thanks also to Manchester Radio On-Line for making BTF their charity of the month. See Emmet Hynes' report on page 5, on the spooky goings on during the event!

The Roger and Jean Jefcoate Trust for their generous donation of £4000 for volunteer training.

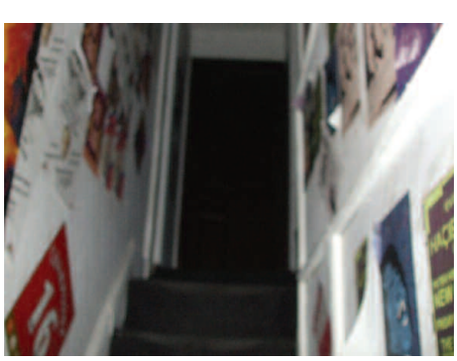
Pictured above back row left to right: Dave Foran (MRO DJ), Emmet and Gary. Front row left to right: Jo, Michelle, Jackie, Stephen and Micheala. All from Eastlands Homes Community Safety Team.

HAUNTED NIGHT

BTF member and Greater Manchester Police Officer, Emmet Hynes, describes a sponsored overnight stay in a 'haunted' building to raise funds for BTF:

On the 1st November 2008 a sponsored haunted evening took place involving myself, my wife and some of her work colleagues from Eastlands Homes Community Safety Team (EMCST). The idea was that a group of us remain overnight in a 'haunted' building next to the studios of Manchester Radio On-Line (MRO). During the night I took photographs including two photographs, shown here, taken of a stairwell in the house. They were taken only seconds apart and the settings on the camera were the same on both, only the second picture came out blood red for some unknown reason. We found out, however, that the premises we stayed in used to be a place in the early 1800s where 'gentlemen' would frequent to seek female company for a few pennies. Apparently legend has it that the 'lady' of the house was thrown down these stairs and killed by the 'man' of the house.

During our time in the cellar of the house, I managed to record many orbs *(highly variable range of paranormal phenomenon without verifiable causation-including invisible spirits, auras, angels, ghosts, energy fields, psychoenergetic artifacts, and energy balls)*. All of us felt extremes in temperature and discomfort in areas where it is legend a man had been beaten to death and a woman who was killed was hung in an attempt to cover up the murder!



Picure taken in stairwell during overnight stay in 'haunted' building

We held a séance on the top floor of the building during which we placed a video recorder on a table in the corner of the room. Afterwards on reviewing the tape, many orbs could be seen along with dark shadows and a blood-curdling cry of a woman was heard on the tape, which no one had heard during the actual séance. It was about that time that the camera appeared to be moving of its own accord! All of this has made me far less of a sceptic and the fright was worth every penny that we raised for BTF. Many thanks to the Eastlands Homes Community Safety Team and Manchester Radio On-Line Team for their help and support and to everyone who sponsored us with this endeavour.

Picture of stairwell on the left taken seconds later with unexplained red colouring!

NEW BTF LOCAL SUPPORT GROUPS

We are delighted to announce that we have two new BTF local groups starting in Birmingham and North Tyneside. For further information about these groups please see the section 'Local Groups' in this issue.

THE DIAGNOSIS AND MANAGEMENT OF PRIMARY HYPOTHYROIDISM

A statement made on behalf of the Royal College of Physicians, in particular the Royal College of Physicians Patient and Carer Network and the Joint Specialty Committee for Endocrinology & Diabetes, The Association for Clinical Biochemistry, The Society for Endocrinology, The British Thyroid Association, The British Thyroid Foundation Patient Support Group and The British Society of Paediatric Endocrinology and Diabetes.

Endorsed by the Royal College of General Practitioners

1 Introduction

(a) Hypothyroidism, underactivity of the thyroid gland, is common. It can make people unwell and should be treated with thyroxine (T4) tablets. Symptoms of hypothyroidism, for example tiredness, are not specific for thyroid underactivity and occur in many other situations. It is important to diagnose hypothyroidism with a blood test, because it can be dangerous to take T4 or other thyroid hormones if they are not needed. We are therefore very concerned that some patients with and without thyroid disease are being inappropriately diagnosed and managed, using thyroxine and other thyroid hormones, in ways which compromise patient safety. This is potentially an enormous problem, given that in any one year one in four of the population has their thyroid function checked.

(b) The vast majority of patients with suspected thyroid disease are supported very well in primary care by their General Practitioners and their condition, hypothyroidism or otherwise, is appropriately diagnosed and well managed. However some patients are inappropriately diagnosed as being hypothyroid (often outside the NHS) and are started on thyroxine or other thyroid hormones which will not only cause them possible harm but leaves the true cause of their symptoms undiagnosed and therefore untreated.

(c) This statement refers only to primary hypothyroidism. Secondary hypothyroidism is a different condition and should be managed by accredited endocrinologists in the same way as all other pituitary diseases.

2 Diagnosis of primary hypothyroidism

(a) The symptoms of hypothyroidism are very common, both in many other conditions and even in states of normal health. It is therefore essential that thyroid function is tested biochemically alongside a careful clinical assessment of the individual patient. Clinical symptoms and/or signs alone are insufficient to make a diagnosis of hypothyroidism.

(b) The only validated method of testing thyroid function is on blood, which must include serum thyroid stimulating hormone (TSH) and a measure of free thyroxine (T4).

(c) There is no evidence to support the use of thyroid hormone testing in urine, saliva, etc or the measurement of basal body temperature in the diagnosis of thyroid dysfunction.

(d) The results of blood tests for thyroid function can be influenced by other factors, for example in some illnesses which do not permanently damage the thyroid gland. In this case the tests will return to normal after the illness and thyroid hormone therapy is not needed (and can be harmful).

(e) We recognise that different test methods can give different results and we support the international initiative for greater harmonisation of reference ranges and of the units used in expressing results.

3 Treatment of primary hypothyroidism

(a) The aim of the treatment of hypothyroidism is to render the patient back to the normal or 'euthyroid' state.

(b) When a sufficient dose of thyroid treatment is given to lower the TSH to the normal range (reference range) for the test method used, patients usually lose their symptoms of hypothyroidism.

(c) Fine-tuning of TSH levels inside the reference range may be needed for individual patients.

(d) Patients with continuing symptoms after appropriate thyroxine treatment should be further investigated to diagnose and treat the cause.

(e) Overwhelming evidence supports the use of thyroxine (T4) alone in the treatment of hypothyroidism. Thyroxine is usually prescribed as levothyroxine. 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.

(f) There are potential risks from T3 therapy, using current preparations, on bone (eg osteoporosis) and the heart (eg arrhythmia). We note that the extract marketed as Armour thyroid contains an excessive amount of T3 in relation to T4. Over-treatment with T4, when given alone, has similar risks.

4 Treatment of sub-clinical hypothyroidism

(a) Sub-clinical hypothyroidism is defined as being present in a patient when the TSH is above the upper limit of the reference range but Free T4 levels are within the reference range.

(b) Some patients, particularly those whose TSH level is greater than 10mU/l, may benefit from treatment with thyroxine in the same way as for hypothyroidism as above, as indicated in national guidelines (Thyroid function testing, Association of Clinical Biochemists, British Thyroid Association, British Thyroid Foundation, July 2006: http://www.british-thyroid-association.org/info-for-patients/Docs/TFT guideline final versionJuly 2006.pdf

5 Patients with normal thyroid function tests

(a) We recommend that those patients whose thyroid blood tests are within the reference ranges but who have continuing symptoms, whether on thyroxine or not, should be further investigated for the non-thyroid cause of the symptoms.

(b) A further opinion or help with these patients may be sought from appropriate specialists on specialist registers of the Royal College of Physicians or the Royal College of Paediatrics and Child Health.

6 Conclusion

(a) Patients with suspected primary hypothyroidism should only be diagnosed with blood tests including measurement of TSH.

(b) Patients with primary hypothyroidism should be treated with T4 using levothyroxine tablets alone.

(c) There is no indication for the prescription of T4 or any preparation containing thyroid hormones to patients with thyroid blood tests within the reference ranges.

(d) In patients with suspected primary hypothyroidism there is no indication for the prescription of T4 or any preparation containing thyroid hormones to patients with thyroid blood tests initially within the normal range. Thus patients with normal T4 and TSH do not have primary hypothyroidism and even if they have symptoms which might suggest this should not be given thyroid hormone replacement therapy.

(e) The College does not support the use of thyroid extracts or thyroxine and T3 combinations without further validated research published in peer-reviewed journals. Therefore, the inclusion of T3 in the treatment of hypothyroidism should be reserved for use by accredited endocrinologists in individual patients.

(g) Laboratories which measure thyroid function in other bodily fluids besides blood need to provide analytical and clinical validation to demonstrate their efficacy.

(h) The above statements reflect best practice of clinical endocrinologists accredited by the Royal College of Physicians and the Royal College of Paediatrics and Child Health.

19th November 2008

WHY DON'T WE MEASURE THYROID HORMONES IN SALIVA AND URINE?

In the 1970s researchers looked at whether the measurement of thyroid hormones in urine and saliva could provide a more accurate assessment of thyroid function than measurement of these hormones in blood. The results of these studies suggested that urine and salivary measurements were less reliable at detecting abnormal thyroid function than the measurement of TSH and free thyroid hormones in blood and as a consequence they did not find a place in general routine use. Recently we've had a number of enquiries from our members about this, so we asked the British Thyroid Association to explain the pros and cons of blood versus salivary and

urinary measurements. Many thanks to BTA for the following article:

The usual way of determining if the thyroid is functioning correctly is for the doctor to take a small sample of blood and ask the hospital laboratory to measure the amount of thyroid stimulating hormone (TSH) and the thyroid hormones (T4 and T3) in the sample. By this means it is possible to find out whether the thyroid is producing too much or too little T3 and T4. Such a combination of blood tests has proved effective at detecting even the most minor abnormalities in thyroid function.

Before they can work, thyroid hormones have to get from the blood into the cells of the body. Most of the T3 and T4 in the blood are bound to proteins that prevent the hormones from gaining access to cells. A tiny portion of T3 and T4 in blood is not bound to protein and is known as the "free T3"and "free T4" fraction. Free T3 and free T4 are pumped into the cells of the body, where they move to the nucleus and modify a range of cellular functions including regulation of the metabolic rate. Most laboratories therefore measure free T3 and free T4 in blood, rather than the total concentration of hormone in the circulation.

In the 1970s the techniques available to measure free T3 and free T4 in blood were difficult to perform and very time-consuming. As a consequence, free T3 and free T4 was rarely measured in a routine clinical setting. Urine and saliva are fluids that are derived from blood that has been filtered. These fluids usually contain little or no protein. Because of this filtration process, it was argued that only the "free hormone fraction" would appear in these fluids. It was hoped that the concentration of T4 and T3 in saliva or urine might thus reflect the free T3 and free T4 concentration in blood. A number of research studies have been performed to determine if measuring the amount of T3 and T4 in urine or saliva can provide a convenient and reliable means of assessing thyroid function. As detailed below, these studies uncovered a number of significant problems, and urine and salivary measurements were never widely adopted and were abandoned when simple laboratory methods to measure free T3, free T4 and TSH in blood became available in the late 1980s.

Measuring thyroid hormones in saliva

Salivary measurements of thyroid hormones do not mirror the levels of free T3 and free T4 in blood. The concentration of thyroid hormones in saliva appears to be much higher than would be predicted from the known free hormone concentrations in blood [1, 2]. Salivary measurements may also give a misleading indication of thyroid status. The concentration of thyroid hormones in saliva is affected by the rate of saliva production; thus salivary T4 concentration appears to rise just before meals when saliva production increases [2, 3]. The presence of even small contaminating amounts of blood in saliva (that can occur after brushing teeth) also produces a significant increase in salivary thyroid hormone concentration. There is also evidence that T4 in saliva may vary in the same individual when measured on consecutive days [3]. For these reasons the concentration of thyroid hormones in saliva is unlikely to give an accurate index of thyroid status [2-5].

Measuring T3 in urine

Urinary measurements of T3 are unreliable for identifying patients with hypothyroidism since they may be normal in up to 50% of patients who have the disease [6]. Furthermore any severe illness not related to the thyroid [7], or even simply fasting [8] can produce a large decrease in urinary T3 excretion. Thus a normal urinary T3 level does not exclude hypothyroidism, whilst a low urinary T3 can be caused by illness not related to the thyroid.

As well as simply filtering the free thyroid hormone fraction from blood, the kidney has additional mechanisms that can actively control the amount of T3 and T4 that appears in urine [8]. Low urinary excretion of T3 and T4 is found in patients with poor kidney function [9] and also in young babies where the processes that control the excretion of T3 and T4 by the kidney have not fully developed [10]. Patients who have protein in their urine, due to kidney disease, have markedly increased amounts of T3 and T4 in the urine [9].

Measuring T4 in urine

If kidney function is normal and a patient is otherwise healthy and eating normally, the excretion of T4 in urine correlates better with thyroid status than urinary T3. However, as for T3, the amount of T4 excreted in urine is decreased by fasting [8] and impaired kidney function [9]. Urinary T4 assays offer no advantage over that of measuring free T4 in blood [6, 11] and, like urinary T3, may produce misleading results in some circumstances.

Conclusions

Salivary or urinary measurements of T3 and T4 have no advantage over the measurement of free thyroid hormones in blood. More importantly, in some circumstances, salivary or urinary measurements can produce misleading information regarding a patient's true thyroid status.

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Research News

BRITISH THYROID FOUNDATION

Registered Charity No. 1006391

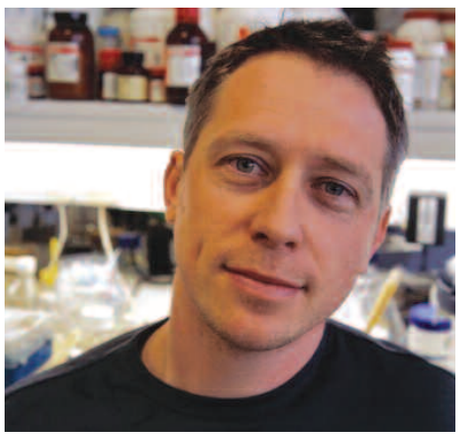
BRITISH THYROID FOUNDATION RESEARCH AWARD 2008

This year the BTF is, once again, able to fund two research awards and we are delighted to announce that the recipients are: 1. Dr Christopher McCabe, University Birmingham for his study entitled 'The role of PBF – a novel binding partner of p53 – in differentiated thyroid cancer' and 2. Dr Tim Cheetham, University of Newcastle for his study entitled 'A randomised study of two anti-thyroid drug treatment regimens in young people with thyrotoxicosis'.

1. The role of PBF – a novel binding partner of p53 – in differentiated thyroid cancer – Dr C McCabe

Thyroid cancer has been shown to have many different causes. One gene that has been implicated in the aetiology of thyroid cancer is called PBF. This gene was shown to be highly expressed in thyroid tumours, and to induce tumour formation in mice. However, very little is known about how PBF works in the cell.

We now have new and exciting data, which suggest that PBF is able to attach to the extremely critical protein p53, which is a major regulator of how a cell behaves if its DNA gets damaged. One outcome of DNA damage is called genetic instability, which can arise if p53 does not function correctly. Genetic instability – literally, an unstable or mutated set of genes within a cell – is often a cause of cells escaping normal regulation and growing to form tumours.



Pictured above: Dr Christopher McCabe.

Our novel idea, which is supported by our preliminary experiments, is that PBF is highly expressed and attaches to p53, interfering with its ability to respond to damaged DNA. The thyroid gland is well known to be sensitive to radiation, so we will irradiate thyroid cells, which will damage their DNA. We can then compare the ability of p53 to carry out its normal function of switching other genes on and off, when it is in the presence of low levels and high levels of PBF.

The way we will alter the level of PBF comes from a mouse model we have very recently constructed. We have confirmed that the thyroids of these mice have very high levels of PBF, and we are currently examining whether they are prone to thyroid tumours. What we will do in this proposal, however, is to take thyroid cells from normal mice and from our model, and grow them in plastic dishes. We will then irradiate the cells, and will determine how p53 is able to turn on and off 84 genes that it is know to control when it is subjected to low or high levels of PBF.

The second part of our investigation will be to examine the relationship between PBF and p53 in human thyroid tumours, along with normal thyroid tissue from the same patients. We will compare the amount of PBF present with the degree of genetic instability. We will also examine the p53 gene to see if it is mutated. Because we have clinical data from all of our patients, we will be able to see whether PBF levels, p53 status and genetic instability correlate with the severity of the tumour. This will be gauged through assessing the tumour size, whether it was invasive and whether it later recurred. We will also look at the sex and age of patients and various other clinical parameters. In this way, we will be able to see whether our experimental outcomes are mirrored by clinical associations, telling us whether the interaction between PBF and p53 that we have witnessed in our experiments can yield important insight into how thyroid tumours develop and grow.

The University of Birmingham has a very strong track record in employing strict animal welfare safeguards, ensuring that no unnecessary animal suffering is allowed to occur.

2. A randomised study of two anti-thyroid drug treatment regimens in young people with thyrotoxicosis – Dr T Cheetham

Around 120 young people (under the age of 16 years) present with thyrotoxicosis (an overactive thyroid gland) every year. Most will be treated initially with anti-thyroid drugs (usually Carbimazole, occasionally Propylthiouracil).

Pictured above: Dr Tim Cheetham.

Anti-thyroid drugs (ATD) can be used in one of two main ways:

- 'Block and replace' treatment (BR). This is where thyroid hormone production by the over-active thyroid gland is switched off completely by ATD and thyroxine is then added in a 'replacement' dose.
- 'Dose titration' treatment (DT). This is where the dose of ATD is adjusted so that hormone production by the overactive gland is reduced to normal.

Both BR and DT therapy have potential advantages and disadvantages. Potential advantages of the BR approach include:

- More stable thyroid function tests.
- A reduced number of blood tests and visits to hospital

- A reduced likelihood of the over-activity returning when the ATD is stopped.

Potential advantages of the DT approach include:

- Fewer side effects with a lower ATD.
- Improved compliance on one rather than two medications because the DT approach involves taking just ATD and not thyroxine as well.

A recent study suggested that DT was probably best in adults although some adult physicians feel that there are still very good reasons to use BR. A particular consideration in the young person is the fact that they are growing and developing and it may be that more stable blood tests are particularly desirable at this time of life. Hence the BR approach may prove to be the preferred option in the young.

A study looking at the two approaches has been underway in the UK for three years and a number of centres are already taking part including: Birmingham, Cambridge, Edinburgh, Glasgow, Oxford and Newcastle. A number of factors are being looked at as part of the study including the likelihood of the over-activity persisting in the long term, how often thyroid function tests are normal and the frequency of side-effects. We are also collecting blood from the young person and their parents to look at some of the genetic factors that might affect whether someone gets the thyroid problem in the first place.

Patients in recruiting centres are given the option of taking part in the study, which doesn't involve extra blood tests, or extra visits to hospital. We have recruited 30 subjects to date but require 160 and we need to employ someone to work for several hours each week on the study. This person will be responsible for helping centres to recruit patients, helping with administrative aspects of the study and for data entry. This is an important stage of the study and the appointed person will help to ensure that the required numbers of patients are recruited. This funding from the British Thyroid Foundation will also facilitate adoption by the Medicines for Children Research Network, which will also help to boost recruitment.

Learning how best to use anti-thyroid drugs is very important because it will provide families and health-care professionals with information about short- and longer-term outcome, which they can use when making a decision about treatment.

If you are the parent of a young person currently undergoing treatment for an overactive thyroid, should you and they be willing to take part in this study, please speak to the consultant treating the young person about your wish to take part and ask him/her to contact Dr Tim Cheetham at Newcastle University- email: tim.cheetham@nuth.nhs.uk for further information. Thank you.

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BRITISH THYROID FOUNDATION – THE EVELYN ASHLEY SMITH NURSE AWARD – 2008

We are delighted to announce that the recipient of the BTF Evelyn Ashley Smith Nurse Award for 2008 is Linda Goss, Senior Clinical Nurse Specialist in Endocrinology at The Royal Devon and Exeter NHS Foundation Trust, who is undertaking a study entitled 'Improving the care of people receiving radioiodine treatment' and who plans to use the award to attend a conference and present data from her study. We send her our congratulations and wish her every success with this very worthwhile study. We look forward to hearing the results in due course. Linda has sent in the following article giving details of her project:

Improving the care of people receiving radioiodine treatment

Radioiodine therapy is widely used for the treatment of thyrotoxicosis and thyroid cancer and is increasingly being used for the management of euthyroid (normal thyroid function) goitre. Over recent years various studies have identified that people feel worried and concerned about having radioiodine treatment. These studies also identify that the treatment can cause fluctuations in thyroid hormone levels in the early period following administration and that this may affect individuals' quality of life, health and well-being. Research shows that there are inconsistencies in the advice given regarding the necessary precautions and in the medication regimes used in the early period following radioiodine treatment.

In 2003 an audit of our practice regarding radioiodine treatment in Exeter identified several key deficiencies – lack of follow-up at an appropriate time, inconsistency in medication regimes following radioiodine (for example, some people were prescribed a combination of antithyroid drugs and thyroxine replacement and some were monitored and prescribed medications as necessary), inconsistency in advice regarding precautions and patient worries about radioiodine treatment.

We decided to address these deficiencies by the introduction of a nurse-led thyroid clinic and by conducting a research study.

The aim of the nurse-led clinic was to improve the quality of care for patients receiving radioiodine treatment. The patient pathway for radioiodine treatment has been clarified and all patients are now seen by an endocrine specialist nurse when they are referred for radioiodine. This ensures that consistent and appropriate information is given to ensure informed decision-making and consent by the patient.

Pictured above: Senior clinical Nurse Specialist, Linda Goss.

Counselling is given regarding radioiodine treatment and appropriate precautions. This information covers the following:

- What is radioiodine
- How radioiodine works
- How will the radioiodine be administered
- Instructions to help reduce the risk of radiation exposure to others i.e. physical contact with others especially children and pregnant women, hygiene and food preparation, laundry, pet care, increasing fluid intake, and precautions on public transport
- Sanitation facilities at home and continence issues
- Family planning
- The effect on patients' employment e.g.

food preparation, photographic film and caring/childcare

- Travel and holidays especially the risk of triggering airport alarms
- Radionuclide instruction card and disk
- Instructions and advice regarding thyroid eye disease if appropriate
- Medication
- Follow up
- Telephone helpline

Written information is provided to reinforce the verbal information given and also provides the telephone numbers for the radioiodine and endocrine telephone advice lines. The patients are then seen at a one-stop visit for the administration of radioiodine treatment.

I see all the patients six weeks after radioiodine treatment. The patients have their thyroid function checked a few days prior to their consultation to enable assessment of their clinical and biochemical thyroid status. Information, counselling and support are given to address patient concerns and worries. The patients are observed for occurrence or progression of signs and symptoms of thyroid eye disease. As a non-medical prescriber, I am able to review medications and provide appropriate information and education. Adjustments in medications and doses are made according to the patient's thyroid status and a predefined local protocol. As a non-medical prescriber I am able to provide a complete package of care for the patients. This has also improved continuity of care and reduced waiting time for prescriptions.

I review the patients on a six-weekly basis for the first six months following radioiodine. Some consultations may be undertaken on the telephone depending on the patients' clinical condition and suitability. The patients' thyroid function will be checked prior to all consultations in the post radioiodine period. Telephone consultations have proved to be beneficial to both patients and the service. It negates the need for patients to take time off work for the appointment and the time and costs of travelling into the hospital. It also increases capacity within the clinic for other patients who need to be seen.

Patients who are not receiving antithyroid medication post-radioiodine have thyroxine or antithyroid medication commenced according to their biochemistry and clinical condition during the first six months. Patients who are taking antithyroid medication and thyroxine in a block and replace regime continue to do so for six months and have the thyroxine dose adjusted according to their biochemistry and clinical condition. All patients are reviewed at six months following radioiodine. This is to establish patients' thyroid function after a six-month time period in which the radioiodine will have had its effect, therefore enabling us to assess the efficacy of radioiodine treatment.

The research study we are undertaking is looking at which medication regime in the post-radioiodine period offers better quality of life and well-being to patients. Another secondary aim is to compare thyroid hormone levels following radioiodine and to determine if one medication regime offers more stability over the other regime.

The award will enable me to attend a national/international conference where it is hoped I will present data from our study. This will also provide me with an opportunity for further learning and networking and sharing ideas and experiences with others.

THYROID LEVELS MAY AFFECT WOMEN'S CHANCES OF DEVELOPING ALZHEIMER'S

Women with low or high levels of the hormone thyrotropin appear to have a higher risk of developing Alzheimer's disease, according to a report entitled "Thyroid Function and the Risk of Alzheimer's Disease" published last July. The authors emphasise however that the findings should be further tested before drawing clinical conclusions.

The study, which was published in the Archives of Internal Medicine (a journal of the American Medical Association), was conducted by Dr Zaldy Tan and colleagues from the Hebrew Senior Life, Beth Israel Deaconess Medical Center and Harvard Medical School, Boston, and focused on measuring thyrotropin (also known as Thyroid Stimulating Hormone, or TSH). They measured levels in nearly 2,000 men and women without cognitive problems and with an average age of 71 between 1977 and 1979. The participants—part of the long-term community-based Framingham Study—were assessed for dementia at that time and again every two years.

After nearly 13 years of follow-up, 209 participants developed Alzheimer's disease. After adjusting for other related factors, the researchers found that women with the lowest and highest levels of thyrotropin had more than double the risk. However, no such relationship was seen in men.

"Whether altered thyrotropin levels occur before or after the onset of Alzheimer's disease, the neuropathologic mechanism is unclear," the authors write. Changes in the brain caused by Alzheimer's disease may reduce the amount of thyrotropin released or changes in the body's responsiveness to the hormone, say the researchers. Alternatively, low or high thyrotropin levels could damage neurons or blood vessels, they say.

The authors conclude that "These findings should be considered hypothesis–generating and should be validated in other populations before clinical conclusions are drawn."

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THYROID DISEASE AND GLAUCOMA

There have been two studies published recently that look at a possible connection between thyroid disease and glaucoma. One study suggests that people with thyroid problems may run an increased risk of developing glaucoma. This study, by Dr J.M. Cross and colleagues from the University of Alabama at Birmingham, was published in the November issue of the *British Journal of Ophthalmology*.

The aim of the Birmingham study was to examine the association between a history of thyroid problems and a history of glaucoma among more than 12,000 participants from the US-based 2002 National Health Interview Survey.

Among those interviewed, 4.6% had glaucoma and nearly 12% reported a history of thyroid problems. The prevalence of glaucoma was 6.5% in those who reported thyroid problems, compared with 4.4% in those who did not report thyroid problems. This association remained after adjusting for age, gender, race, and smoking status.

The authors conclude that "the results of this study lend support to the hypothesis that thyroid disorders may increase the risk of glaucoma. Research should continue evaluating potential mechanisms

underlying this relationship and whether the treatment of thyroid problems reduces subsequent glaucoma risk."

In another article published in the journal *Ophthalmology* in September, researchers assessed the association between hypothyroidism and the development of open-angle glaucoma (OAG) in 4,728 patients aged over 60 who had been newly diagnosed with OAG and could not make an association with prior hypothyroidism. The authors, Dr SP Motsko and Dr JK Jones of the Degge Group, Arlington, Virginia, suggest that the large proportion of patients who were already receiving thyroid replacement therapy may have negated any OAG-related consequences of hypothyroidism.

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Letters and Comments

We welcome letters from our members but, owing to restricted space, letters will be subject to editing at the Editor's discretion. Please understand that medical comments are given for information only and cannot replace a personal consultation with your doctor or specialist. You should not alter the recommended treatment issued by your personal physician without their knowledge and agreement. We advise you to consult with your GP or specialist with regard to further treatment choices or advice.

Thyroxine and breast cancer

Mrs DH asks: Is there a connection between thyroxine and breast cancer and could taking synthetic thyroxine be an issue?

Our medical adviser comments: *Several studies have identified an association between autoimmune thyroid disease and breast cancer, although the subject remains controversial. The best current advice is that appropriate thyroid hormone replacement is not likely to have adverse effects on breast cancer. Breast cancer patients with hypothyroidism should receive thyroxine replacement with the goal of maintaining T4 and TSH levels within the normal range.*

We will return to this subject in more detail in a later issue – Ed.

Thyroid function and Gaviscon

Mr CJH writes: In June 1993 my former GP prescribed Gaviscon original liquid, aniseed flavour, for my acid reflux problem. Nine years later I began making frequent visits to my GP with a variety of aches, pains and weight loss. In November 2002 my GP arranged for comprehensive tests of my blood, one of which showed that I was thyrotoxic (hyperthyroidism) and my GP then prescribed carbimazole.

In July 2005, the NHS stopped doctors prescribing Gaviscon original liquid and they were advised instead to prescribe Gaviscon Advanced. Shortly after the changeover, my thyroid returned to normal functioning. I was puzzled by this and started to compare the ingredients of both Gaviscon liquids.

I believe the erythrosine (E127 colouring) in Gaviscon original may have caused my thyroid to become thyrotoxic. I estimate that between June 1993 and November 2002 the amount of erythrosine that I ingested through taking the Gaviscon was at least 580mg. I would be interested in the views of your medical advisors and I would also like to hear from any members of BTF who have suffered from hyperthyroidism in similar circumstances.

Our medical adviser comments: *Yes, there is iodine in erythrosine and I think it is possible that it could interfere with thyroid function but this is not frequently cited as a problem.*

If you have had a similar experience to Mr CJH and would like to contact him, please write in and we will be happy to forward your letter – Ed.

Combination T4/T3

Mr PM writes: I read with great interest the Case History in the Autumn 2008 issue of BTF News about the benefits of T4/T3. How many more of these cases must there be before the medical profession changes its official stance. T4 may be fine for most people, but some have long-term fatigue problems that doctors ignore (or treat with anti-depressants).

Miss AS says that her GP found a consultant (at last) who was willing to try T4 plus T3, and it worked for her. My treatment is under my GP, and he can treat me as he chooses. After many years on T4 alone, I told him I would like to try Armour (desiccated thyroid extract), and he agreed. After a time I asked to be seen by a consultant. The consultant preferred T3 to Armour and I agreed with my GP that I would change to T4/T3 (but I could have kept on Armour if I wanted to). I am not sure which is best, as I still get tired, but at least I have tried the options.

In the same issue you printed an article by Bijay Vaidya and Simon Pearce, which seems to be the 'official line' on treatment of hypothyroidism. This states 'current evidence does not support a clinical benefit from combination T4/T3' but it does not mention that some consultants will try it for a period if the patient is not happy with T4. It would be so much easier if the information available to GPs was not so certain that T4 was the only answer.

Our medical adviser comments: *The commonest reason for people feeling better when on combined T4/T3 therapy or 'Armour' than when they are on thyroxine alone, is that their thyroxine dose was insufficient. In other words, having a TSH in the normal range is not sufficiently good control, and that is the level of control many GPs aim for. Some people do not feel well with a TSH above 2 or 2.5 mU/l. If you take someone with a TSH of 4 on thyroxine and add in T3, I am not surprised they feel better. The fact is when you take more than 1000 people, keep their TSH well controlled on thyroxine and then randomly swap some to combined therapy, there is no significant difference.*

Subclinical hypothyroidism

Mrs EL writes: In the Autumn 2008 BTF News there is an article entitled 'thyroxine therapy has little benefit in patients with subclinical hypothyroidism'. I must disagree with you on this.

I have been on only 25 mcg per day of levothyroxine for eight years. My blood is tested every six months but the dose has never been altered. Because I'm on such a low dose, I asked to try coming off it. I did this for three months but had to go

back on it because I got symptoms of withdrawal; my thyroxine (T4) level was normal but my thyroid stimulating hormone (TSH) was rising. Also my cholesterol level rose beyond normal levels. Since I've gone back on the thyroxine my cholesterol and thyroxine levels have returned to normal.

Our medical adviser comments:
Subclinical hypothyroidism (now termed as mild thyroid failure) relates to the thyroid function test results as opposed to the amount of thyroxine you need. Mild thyroid failure is defined as having a raised TSH level (between 4.5 and 10 mU/l) with a normal FT4 (free thyroxine) level and absence of symptoms. The evidence from trials of thyroxine replacement in such patients is that they are unable to distinguish T4 from placebo when blinded to their treatment. The occasional patient has symptoms and responds to low dose thyroxine, which may be the case in this instance, although some people with mild thyroid failure have in fact felt worse when taking the thyroxine replacement.

Taking levothyroxine with food

NB asks: I read with interest the article in the autumn issue newsletter entitled 'The Management of Hypothyroidism', which stated 'as the absorption of levothyroxine is significantly affected by food, the tablet should be taken on an empty stomach'. Not once has any medical practitioner or endocrinologist ever advised me to do this. I have been treated for hypothyroidism for over eleven years and take my tablet after breakfast. I have an annual blood test and there have been no problems. Please can you advise that this statement is correct? I am reluctant to make changes to my routine when I am well.

Our medical adviser comments:
Although evidence shows that the absorption of levothyroxine is significantly affected by food, and the tablet should be taken on an empty stomach if you have taken levothyroxine, as you say, for many years regularly after breakfast and your thyroid function tests are within the reference range and you are feeling well then there is no need to change your routine as it would appear adequate thyroxine is being absorbed. However, it may be possible to reduce your dose of thyroxine if you take it at bedtime and on an empty stomach. For those newly diagnosed it would be recommended to take your levothyroxine on an empty stomach.

Children's Corner

A LETTER FROM SHANNON, BTF'S CHILDREN'S EDITOR

Last November, when I was 10, four people in my school were chosen to do some research training with someone from the Children's Research Centre at The Open University. We got to choose what research we wanted to do and I chose to find out what children think about having a thyroid disorder because I have Graves' Disease and I have no-one to talk to.

I chose questionnaires to collect my data because all the children with thyroid disorders live too far away for me to interview. A lady at the British Thyroid Foundation sent out 70 questionnaires for me to all the children that she knew who had thyroid disorders. I got 28 questionnaires back. That is very good because most researchers who send out questionnaires don't get as many back.

My data showed that most children would like to meet other children who understand what it's like to have a thyroid disorder and want to talk about it. They think it isn't fair that adults get support groups and we don't.

Doing the research has helped me to talk about my thyroid more. Some of the children put in letters with their questionnaires saying what a good idea my research was and I even made a pen pal with one of the girls who put a letter in.

If you would like to read my report here is the address: http://childrens-research-centre.open.ac.uk

You can find it by going to Original Research then Group by Year Submitted then Research Submitted in 2008.

When the British Thyroid Foundation saw my research report they thought it was very good and decided that they needed to think about children and what they could do for them. So now they are planning to put children's ideas and how they feel into a special part of their newsletter. They have invited me to become Editor of this section and I would like to invite you to write about yourself and your thyroid disorder and about the problems you might have had and how you have coped. If you have any suggestions for the name of the children's section, please send me any ideas you might have.

You can also write in for information and advice and have your letters published. BTF has arranged for a special doctor who helps children with thyroid disorders to answer your letters in our page of the newsletter.

You can write to me at Children's Editor, BTF News, The British Thyroid Foundation, 2nd Floor, 3 Devonshire Place, Harrogate HG1 4AA. Email: Shannon@btf-thyroid.org

I'm hoping to hear from you very soon. Thank you.
Shannon Davidson, aged 11.

THE THYROID GLAND AND THYROID HORMONE

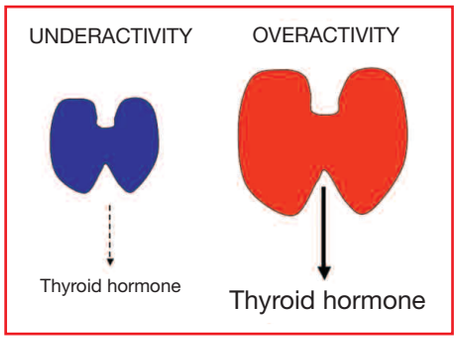
What happens when the thyroid gland stops working properly and what to do about it!

We are delighted that Tim Cheetham, who is one of the BTF research award recipients for 2008 (see Research News in this issue), has agreed to start off our new Children's Corner with this article about what the thyroid gland does and what can happen if it stops working properly.

The thyroid gland is a butterfly-shaped gland that sits in the neck at the front of the wind-pipe or 'trachea'. Sometimes it can be seen at the front of the neck but in many healthy people it can't. The thyroid gland is, in many respects, like a factory. Factories make things and in the case of the thyroid gland the thing that it makes is a natural chemical called thyroid hormone. Thyroid hormone is important because after being made by the thyroid gland it then goes on to help many parts of the body to work properly:

- It helps people to think properly.
- It helps the heart to work properly.
- It helps the abdomen/tummy to work properly.
- It helps the lungs to work properly.
- It helps the bones to develop properly.

The thyroid can sometimes stop working properly and when this happens it usually makes either too much hormone (over-activity) or too little hormone (under-activity). Some young people reading this article will have had an over-active or an under-active thyroid gland and may be on



medicine because of this. You can see the two main groups of thyroid problems in young people – over-activity and under-activity – in the table below and in the picture.

We thought it would be useful to talk about these problems in more detail and will start by talking about 'under-active' thyroid glands first because this is a more common problem.

1. An under-active thyroid gland

a) An under-active thyroid gland in babies – 'congenital hypothyroidism'

Sometimes people are born without a thyroid gland or with a gland that is too small. They don't have enough thyroid hormone because their thyroid gland 'factory' is not properly built. These babies are usually picked up by a blood spot test in early life and are treated with thyroid hormone replacement (otherwise known as thyroxine) which is the same as the natural thyroid hormone. The thyroid hormone replacement can be given as liquid or tablets. Babies and some older children find the tablets can be difficult to swallow but fortunately they can be crushed and mixed with fluid such as milk. Thyroid hormone replacement works very well so an under-active thyroid doesn't stop them doing what they want.

b) An under-active thyroid gland due to antibodies (sometimes called Hashimoto's)

In this condition antibodies (which usually fight bugs such as bacteria or viruses) attack the thyroid gland by mistake and damage it. Sometimes it is obvious that something is wrong because the gland gets big but sometimes it happens without the person knowing anything about it until they become under-active. In this case they may have problems such as tiredness, altered appearance and being quite short. Thankfully this problem is quite easy to treat as well by putting back the thyroid hormone – either as thyroid hormone tablets or liquid.

2. An over-active thyroid gland

a) An over-active thyroid gland (children and teenagers) – also called 'Graves' disease'

Antibodies sometimes make the thyroid gland under-active as we talked about before (1b). However, some antibodies can actually make the thyroid go over-active because they switch the gland on and tell it to make extra thyroid hormone continuously instead of just when it is needed. This can make people feel poorly and stop them from concentrating and sleeping properly. An over-active gland can be more difficult to treat than an under-active one. Some people will be given an 'anti-thyroid' medicine to take by itself (usually a medicine called carbimazole) which reduces the amount of thyroid hormone made by the thyroid gland. The amount can then be adjusted until the thyroid hormone levels are normal. Other people are given a bigger dose which stops the gland from working completely. The body's need for thyroid hormone can then be met by thyroxine to replace the missing hormone.

b) An over-active thyroid gland in babies

Very rarely Mums who are expecting a baby have the over-active antibodies in their blood-stream. The antibodies can cross over to the baby and make the baby's thyroid gland over-active. This doesn't happen often but when it does the baby may need to be looked after very carefully until the antibodies go away.

	Under-active	Over-active
Newborn Babies	'Congenital Hypothyroidism'	Over-activity in newborn babies
Commonest Cause	The thyroid gland hasn't developed properly	Antibodies from Mum switch the thyroid gland on
Children + Teenagers	Hashimoto's Thyroiditis	Graves' disease or thyrotoxicosis
Commonest Cause	Antibodies attack and destroy the thyroid	Antibodies stimulate the switch on the thyroid gland so that it is 'on' all the time

Coming shortly the Medikidz!

The Medikidz are a gang of superheroes from Planet Mediland – they've been created to explain medicine to young people in a way THEY can understand.

Medikidz is a new initiative in children's medical education. Most health educational resources at the moment only target parents - but Medikidz is about to change that! Medikidz will be accessible to children in both print (through comic books, pamphlets and brochures) and online.

Medikidz.com is going to be a 3D virtual world of the human body and within this will be an integrated social network for children globally to connect around illness and disease.

Exciting stuff!

Medikidz is planning to put out comic books explaining hypo- and hyperthyroidism - so watch this space!

See: http://www.medikidz.com

Local Groups

If any member is interested in becoming a BTF local support group co-ordinator or telephone contact, please contact BTF Head Office on 01423 709707, or the regional support group adviser for your area as listed in this newsletter.

Sometimes messages can be difficult to interpret from an answering machine, so if your call is not returned, please call again.

Birmingham

I am the co-ordinator for the newly formed BTF local support group in Birmingham and I am hoping to arrange the inaugural meeting of this group for February 2009. I would be delighted to hear from any BTF members in the Birmingham area who would be interested in attending this meeting. For further details regarding this group and the forthcoming meeting please contact me on 0121 6287435 or email: janetdmp@googlemail.com
I look forward to hearing from you.
Janet

Bolton

We held an extremely successful, informative and entertaining meeting in November when our guest speaker, Professor Tim Dornan, from Hope Hospital and Manchester University, provided a valuable insight and understanding of the psychological problems associated with thyroid disorders.

He began the meeting by asking everyone present to discuss what psychological problems meant to them, then held a discussion about this. The result was a wide range of comments such as tiredness, fatigue, lack of energy leading to irritability, anxiety, feeling very emotional, a feeling of loss of self-worth, mood swings, memory loss, lack of concentration, loss of good health and many others.

Prof Dornan went on to explain that being diagnosed with a long-term illness can be similar to the grieving process, in that you are grieving for your loss of good health. One of the problems with a thyroid disorder is that many of the physical symptoms interfere with the quality of life and in turn may cause psychological problems and that it is important for doctors to recognise and understand this aspect.

As Prof Dornan is involved with the training of medical students, he told us that the feedback from everyone at the meeting was important in helping to train future doctors into looking at the patients' whole quality of life and that treatment should be patient centred.

Our thanks go to Prof Dornan for attending the meeting, which prompted positive feedback from those in attendance; we look forward to his next visit.

Meeting dates for 2009 – Saturday 14th March 2009, Saturday 13th June 2009, Saturday 14th November 2009. All meetings are held 10am – 12 noon at the Barlow Institute, Bolton Road, Edgworth, Bolton.

Many thanks to all those who have made the past nine years a success for the Bolton group and may I take this opportunity to wish everyone a very Happy New Year.

Please do not hesitate to contact me for any further information or if you feel you may be able to offer your help at future meetings: Tel. 01204 853557 or email: inghamcaz@aol.com
Carole

Edinburgh

The Edinburgh Group continues to meet on the last Tuesday of the month (except during school holidays) in Liberton High School, Gilmerton Road, Edinburgh EH17 7PT at 7.15pm. If you would like further information, or would like to help with the group, please contact me on 0131 664 7223
Margaret

Greenwich, London

The next meeting will be held from 2.15pm to 4.30pm on Saturday 16th May 2009, at the Norbert Singer Lecture Theatre, University of Greenwich, Bexley Road, Eltham, London SE9 2PQ. Dr John Miell, consultant endocrinologist, Head of Metabolic Medicine, Director of Acute Medicine, and Dean of Undergraduate Medicine at the University Hospital, Lewisham, will speak on hypothyroidism (underactive thyroid). If you would like to attend this meeting please ring me to book a place.

Director of the BTF, Janis Hickey, will speak to us on Saturday 17th October 2009. More information regarding this will be given nearer the time.

I wish to take this opportunity to apologise for the lack of meetings for this group during the past year, unfortunately due to serious family health problems.

On behalf of the group I wish all the members of BTF a very Happy New Year.

For any further information please contact me on 020 84732579
Davinder

Manchester and Salford

The next meeting will be on Tuesday 17th February 2009 at 7pm in Trinity Church, Chapel Street, Salford. Speaker to be arranged.

For any enquiries or information of future meetings or to receive email updates about meetings, email: nia2311@aol.com
I am also available on 01942 819195 after 6pm
Nia

Milton Keynes

The Milton Keynes team attended the LINks Health Event at Middleton Hall, Central Milton Keynes in October. This event is aimed at the general public to access information on local health and social group services. Our group was just one of the many voluntary groups who took part along with representatives from the local hospital, PCT, Local Council and some private companies. As usual we had many enquiries from the 64 people who registered their attendances at our stall. It was standing room only! This has now become an annual event and already the Milton Keynes team is planning ahead for 2009.

At our Information Event on Saturday 6th December we had Consultant Psychiatrist, Dr Haido Vlachos, from Milton Keynes PCT as our guest speaker. The topic was "The Psychological Problems in Thyroid Conditions". The audience was most impressed with her lively and enthusiastic presentation that provided an insight into some of the psychological issues that can affect people with thyroid disorders. This was an excellent talk, and the conversations I overheard between members and the written evaluations collected after the event showed that it was highly appreciated.

Meeting dates for 2009 at the Pavilion, Open University, with coffee and registration at 10.30am are as follows: Saturday 7th March, 6th June, 12th September and 5th December.

A donation of £1 is requested from all who attend to pay for the room hire. This includes coffee and a biscuit. For any

further information please contact my deputy co-ordinator, Brenda, on 01908 502214 email: 2-jenners@tiscali.co.uk
Wilma

North Tyneside

The newly formed BTF local support group in North Tyneside, will hold an inaugural meeting on Saturday 14th March 2009, from 11am to 1pm at St Edwards Church, Parish House, Coquet Avenue, Whitley Bay. This first meeting will focus on identifying the needs of the group and planning future activities. Professor Simon Pearce from the Royal Victoria Hospital, Newcastle upon Tyne will be joining us for this meeting.
Future dates for meetings include Saturday 13th June 2009 and Saturday 12th September 2009.

If you are interested in joining us for the inaugural meeting on the 14th March or wish to be included for information on future meetings please contact me on 0191 2531765 or email: judith@dryhurst.co.uk
Judith

Oxford

For information on future meetings please contact me:
lesleylovell68@ntlworld.com
or telephone 01235 832696
Lesley

Tadworth, Surrey

For information on forthcoming meetings, or if you feel you would be interested in becoming more involved with this group please telephone me on 01737 352536
Jane

For up-to-date information regarding all local group meetings and for meeting dates that may not coincide with the BTF Newsletter publication, visit the BTF website www.btf-thyroid.org or contact the Local Co-ordinator of the group – details on the back page of this newsletter.

BRITISH THYROID FOUNDATION ©
Registered Charity No. 1006391

The British Thyroid Foundation became a registered charity in 1991.
It aims to provide support and clear information to people with thyroid disorders, to promote a greater awareness of these disorders amongst the general public and the medical profession, to help set up regional support groups and to raise funds for research.

ADDITIONS TO EDITORIAL TEAM

We are pleased to announce that Judith Taylor is the new BTF News Editor, and Shannon Davidson is the editor of the new Children's Corner.
You can reach Judith at editor@btf-thyroid.org and Shannon at shannon@btf-thyroid.org

Newsletter Disclaimer:
The purpose of the BTF newsletter is to provide information to BTF members. Whilst every effort is made to provide correct information, it is impossible to take account of individual situations. It is therefore recommended that you check with a member of the relevant medical profession before embarking on any treatment other than that which has been prescribed for you by your doctor. We are happy to forward correspondence between members, but do not necessarily endorse the views expressed in letters forwarded.

Medical comments in the newsletter are provided by members of the medical profession and are based on the latest scientific evidence and their own individual experiences and expertise. Sometimes differing opinions on diagnosis, treatment and management of thyroid disorders may be reflected in the comments provided, as would be the case with other fields of medicine. The aim is always to give the best possible information and advice.

If you have any comments or queries regarding this publication or on any matter concerning the British Thyroid Foundation we would be pleased to hear from you.

BTF REGIONAL SUPPORT GROUP ADVISERS:

South East	Jane 01737 352536	**North**	(and thyroid cancer contact)	Carole 01204 853557
South West	Bob 01202 722784			

OFFICIAL BTF LOCAL CO-ORDINATORS:
Our co-ordinators will also be happy to take general calls on all aspects of thyroid disorders

Birmingham	Janet **(PC,CS,RIC)** 0121 6287435	**Liverpool**	Sue **(U)** 0151 2814700
Bolton	Carole **(FC,CS,RIC)** 01204 853557	**Manchester**	*****Nia **(U)** 01942 819195
Edinburgh	Margaret **(C)** 0131 6647223	**Milton Keynes**	Wilma **(U)** 01908 562740
Greenwich, London	Davinder **(U)** 020 84732579	**North Tyneside**	Judith **(U)** 0191 2531765
Henley-on-Thames	Paul **(O,TS,U)** 01491 574934	**Oxford**	Lesley **(U)** 01235 832696
Leeds	Angela **(U)** 01943 873427	**Tadworth, Surrey**	Jane **(GR,RI,TED,G,U)** 01737 352536

OFFICIAL BTF TELEPHONE CONTACTS:

Penny	**(Ch)** 01225 421348	**Chris**	**(U)** 01462 711475
Dave	**(PC,CS,RIC)** 07939 236313	**Fiona**	***(C,HCN,CS,RIC) 01926 853320
Jackie	**(PC,CS)** 01344 621836	**Collette**	*(U,ITSH) 01695 721281
Anne	**(PC,CS)** 01484 510888	**Chris**	*(PC,FC,CS,RIC) 01840 213171
Gay	**(G,TS)** 0208 8469101	**Sandra**	*(U) 0151 4748884
Christine	**(FC,CS,RIC)** 01493 721354	**Sue**	**(PC,CS,RIC)** 01909 732476
David and Mina	01594 810677	**Christine**	**(C,CS,RIC)** 01387 256776
Sheryl	**(U)** 029 20610090	**Anna**	****(P-op H) 01202 255159
Janet	**(O)** 01322 225470	**Brenda**	**(U)** 01908 502214
Jane	**(C,TC-P)** 01522 872331	**Peter**	*****(TED,GR) 01200 429145
Olwen	**(O,RI,U)** 01536 513748	**David**	**(U)** 01708 223375
Wilma	**(U)** 01592 754688	**Lucy**	**(GR,RI,U)** 0117 9424396

*** 9am to 5pm only ** Afternoons only *** After 7pm **** 10am to 12 noon Mon-Fri ***** after 6pm weekdays and anytime weekends**

KEY

O	Overactive thyroid	**TED**	Thyroid eye disease	**GR**	Graves' disease	**TC-P**	Thyroid cancer in pregnancy
CS	Thyroid cancer surgery	**Ch**	Thyroid disorders in children	**TS**	Thyroid Surgery (non-cancer)	**G**	Goitre
U	Underactive thyroid	**H**	Hashimoto's	**H**	Hashimoto's	**RI**	Radioiodine treatment
PC	Papillary cancer of the thyroid	**RIC**	Radioiodine treatment in cancer	**FC**	Follicular cancer of the thyroid	**C**	Cancer of the thyroid
ITSH	Isolated TSH deficiency			**P-op H**	Post-op Hypoparathyroidism	**HCN**	Hürthle Cell Neoplasm

AMEND – Information on medullary thyroid cancer.
Contact: Jo Grey 01892 525308 email: jo.grey@amend.org.uk
website: www.amend.org.uk

Butterfly Thyroid Cancer Trust – is the first registered charity in the UK dedicated solely to the support of people affected by thyroid cancer and is available to patients nationwide. Contact: Kate Farnell 01207 545469 email: enquiries@butterfly.org.uk
website: www.butterfly.org.uk

Thyroid Cancer Support Group – Wales
08450 092737 email: thyroidgroup@tiscali.co.uk
website: www.thyroidsupportwales.co.uk

Thyroid Eye Disease Charitable Trust:
TEDct, PO Box 2954, Calne SN11 8WR 0844 8008133
email: ted@tedct.co.uk

Thyroid Federation International
Website: www.thyroid-fed.org

British Thyroid Association
Website: www.british-thyroid-association.org

All enquiries to:
The British Thyroid Foundation, 2nd floor, 3 Devonshire Place, Harrogate, North Yorkshire HG1 4AA Tel 01423 709707 or 01423 709448 Website: www.btf-thyroid.org
Office enquiry line open: Mon to Thurs, 10am - 2pm.
In the event of a complaint, please address your correspondence to 'The Chair of Trustees'.

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