Registration now open for the second BTF Children’s Conference

Following on from the success of the first Children’s Conference we held in Leeds in 2014 our second conference will be in London on Saturday 13 May 2017. The day will be made up of talks and workshops by medical specialists on all thyroid disorders in children and how to manage them, plus question and answer sessions. It will also be a unique opportunity for parents to meet others in similar situations. One mum who attended the first conference told us that the aspect of the day she most enjoyed was the chance to meet other parents: ‘I feel that seven years of worry about my child were lifted from my shoulders as everyone seemed to have very similar experiences and reactions.’

This free conference will take place at the Abbey Centre in Westminster on Saturday 13 May 2017. If you are interested in coming along please complete the registration form on our website: http://www.btf-thyroid.org/projects/children/302-children-s-conference-2017 or email children@btf-thyroid.org for more information.

Take on a challenge!

We have a few places left in two sell-out runs: The Vitality British 10k London Run on 9 July 2017 – staged on the world’s greatest road race route through the heart of Central London passing many of the capital’s historic landmarks, and the iconic Morrisons Great North Run on 10 September 2017 – the world’s largest half marathon with over 57,000 participants of all abilities – from world class athletes such as Mo Farah to first-timers. So whether you’re out to beat your personal best or are a novice runner, challenge yourself this year and help us support thyroid patients. Email fundraising@btf-thyroid.org for an application form.

Don’t fancy running? Organise a sponsored walk or cycle ride, hold a cake sale, an office collection day or a quiz – the world’s your oyster! Any fundraising you do will help. Download a sponsorship proposal form www.btf-thyroid.org/get-involved/fundraising-and-sponsorship/118-sponsorship-packs
Development of a new drug therapy for the treatment of Graves’ disease

A new drug is being assessed at UK hospital sites for the treatment for Graves’ disease. The trial is funded by Apitope International NV and the European Commission through a Framework 7 grant and has been approved by the Central Research Ethics Committee and the Medicines and Healthcare Products Regulatory Agency (MHRA).

What is the study drug?
The study drug is made from a mixture of two substances called peptides that are found naturally in proteins in the body. The study drug is designed to alter the body’s immune response by stopping the production of the antibodies that have caused the thyroid disorder. This first study in humans will test whether this peptide therapy (the study drug) specifically designed for Graves’ disease, is safe and well tolerated. It is also designed to provide initial information on whether it can improve your body’s immune response and prevent a thyroid disorder from developing.

Who can take part?
Women and men who:
- Are aged 18-65
- Have a diagnosis of Graves’ disease and are not taking anti-thyroid therapy and have not had

ElaTION trial – take part in a trial on a new thyroid nodule examination technique

In BTF News 93 (page 3) we published an item in ‘News’ on a trial called ElaTION that is investigating the potential benefit of using a technique called Real Time Elastography (RTE) alongside the standard ultrasound-guided Fine Needle Aspiration (FNAC) in the examination of thyroid nodules. They are still looking to recruit as many patients as possible so they can be sure that numbers are big enough to make the eventual results reliable.

Who can take part?
If you are aged 18 or over, have at least one thyroid nodule, and have not had a previous FNAC in the last six months.
Support forum set up for Graves’ disease patients

INDIGO is an EU funded project, which is investigating the impact of the food we eat on the micro-organisms that live in our gut (‘microbiome’) and whether this has a role in the development of thyroid and eye disease. www.indigo-iapp.eu

In April INDIGO endocrinologists, ophthalmologists, basic scientists and patient representatives met in Cardiff to review the progress of the project and decided to establish a patient forum to discuss diet etc. (see BTF News 92 page 4).

The forum contains excellent information based on the personal experience of a person with TED and her success in improving her own microbiome. The forum is free to join and can be accessed via the INDIGO www.indigo-iapp.eu/forum-for-patients/

You will need a basic Facebook profile if you would like to participate. You can also join via Facebook: search for ‘Indigo Blog’, and then go to ‘Groups’.

Please contact info@indigo-iapp.eu if you have any questions about accessing the site.

New legacy leaflet

Inside this edition of BTF News is our new legacy leaflet. Information is also available on our website at www.btf-thyroid.org/support-us/232-legacy-giving2

Lulu’s story on YouTube

Sarah Onions, the sister of Lulu, whose story of being born without a thyroid was featured in BTF News 89 (page 8) has had her book ‘Don’t Bring Lulu: Her Family’s Tale of Trial and Triumph’ made available in Kindle format on Amazon.

There are two YouTube films of her story available also – key in Sarah Onions on YouTube.

BTF’s fundraising policy

Please note that we will never telephone you, email or come to your door asking for donations or ask for your bank details.

Email addresses

We would be grateful if you could provide us with your email address to keep our membership database up-to-date. Please email info@btf-thyroid.org with the subject heading Email address. (Please note we will never pass on your details to a third party.)
BTF Projects Update

Iodine project
The iodine group is continuing to promote awareness and knowledge of the iodine situation in the UK and is currently meeting with major supermarkets in efforts to increase the availability of iodised salt products.

Thyroid eye disease
TEAMeD (the UK Thyroid Eye Disease Amsterdam Declaration Implementation Group), which BTF is a key member of, is interested in finding out from thyroid eye disease patients about their experiences of treatment, in order to try and bring about improvements for future patients. For instance they would like to know what support was helpful to you? Was your GP able to help you? What was missing?

The BTF is also working with a group of GPs interested in improving treatment for TED patients and we will pass this information on to them (any information we share will remain anonymous). Please email Janis Hickey at teamed@btf-thyroid.org if you would like to take part.

Children and Teens
Graves’ disease study has started
The Medical Research Council (MRC) funded study that is looking at whether a single dose of Rituximab will improve remission rates in young people aged 12 to 20 years with newly diagnosed Graves’ thyrotoxicosis, has now started (see BTF News 92 page 5). Centres that can recruit patients include Newcastle-upon-Tyne and Birmingham while additional units including Doncaster, Edinburgh, Leeds and Sheffield are expected to take part in the near future. For further details please contact Tim Cheetham (tim.cheetham@nuth.nhs.uk).

Thyroid cancer
The update of the thyroid cancer booklet For Patients, By Patients is almost complete and should be published in the next few weeks. We are very grateful to the patients, volunteers and medical specialists who have contributed their time and expertise to help with this.
**Out and About**

**First UK thyroid cancer conference**

Janis Hickey, BTF Director, attended the Butterfly Thyroid Cancer Trust’s first thyroid cancer conference for patients at the Royal Society for Medicine in London in December. The event gave patients a chance to meet others and to listen to world leading experts in the field. The conference was recorded and can be watched in full by clicking on the links below:

https://youtu.be/cpw5Y0hFd9Y
https://youtu.be/veoG1v5m5QA

**BTF attends British Endocrine Society annual meeting in Brighton**

The BTF attended the annual Society for Endocrinology British Endocrine Societies (BES) conference in November in Brighton. This is the largest UK meeting on hormone research and includes some of the best of British and international science and research, clinical investigation and clinical practice in endocrinology.

The BTF was invited to exhibit in the patient support area. Over the course of the three days the stand was visited by a large number of attendees, many requesting further information to display in their thyroid clinics.

The BTF supported a session on Clinical Thyroidology, which included two talks by BTF Trustees. The first, by Dr Petros Perros was on the best way to manage the increasing diagnosis of incidental thyroid nodules after imaging of the neck for other conditions. The second talk by Dr Mark Vanderpump was on different types of thyroiditis (inflammation of the thyroid gland) and their causes.

Dr Anna Mitchell, Academic Clinical Lecturer in Endocrinology, Newcastle and involved in the TEAMed group which the BTF is a part of, presented the findings at the meeting from a service improvement project set up to ‘fast track’ patients to an early diagnosis of Thyroid Eye Disease (see BTF News 93, page 4).

**Asian Women’s group**

Before Christmas Janis Hickey and Julia Priestley from BTF HQ were invited to meet with a group of Asian women at the Apna Centre in Leeds to talk about the work of the BTF and to raise awareness of thyroid disorders. Many of those present told us they had a thyroid disorder themselves or knew of someone who did, and were grateful for our information.

**Medicines Update**

**Re-introduction of Teva levothyroxine tablets – new strengths and lactose free**

The UK Government has lifted restrictions on Teva levothyroxinie tablets following changes to the formulation and manufacture of levothyroxine tablets.

Teva has undertaken an extensive reformulation of the 50 and 100 mcg tablets, along with manufacturing process improvements that provide assurance of product consistency. In February 2016, CHM reviewed information about the reformulated products and advised that they have an acceptable level of efficacy and safety and could now be re-introduced to the market.

A total of five tablet strengths are now available: 12.5, 25, 50, 75 and 100 mcg.

These products do not contain lactose. They are therefore suitable for patients who have lactose intolerance, as well as the less common but more serious galactose intolerance.

**New tablet strengths introduced**

Teva has also introduced three additional tablet strengths of 12.5, 25 and 75 mcg, two of which are new to the UK market. The new tablet strengths will assist dose adjustment for individual patients, which is an important component of optimal thyroid hormone replacement therapy, whilst avoiding the need to split individual tablets.

**Cancer drug approved in Scotland**

Following a consultation process which included submissions from the BTF, we are pleased to announce that the Scottish Medicines Consortium (SMC) has recommended the use of lenvatinib (Lenvima®) in Scotland. This drug is sometimes suitable for patients with a rare form of progressive, advanced thyroid cancer, which is not responsive to radioactive iodine treatment. The trial results with lenvatinib in this situation were very promising and came on the back of positive trial data with another anti-cancer drug called sorafenib.

Professor Mark Strachan, BTF Trustee and Medical Adviser said: ‘Although these drugs are not suitable for all patients with advanced thyroid cancer, it is extremely encouraging that after decades of limited progress in the treatment of thyroid cancer, we now have two drugs which can be offered to patients with progressive disease’.

Liothyronine (L-T3) and levothyroxine (L-T4) – answering patients’ questions

The management of primary hypothyroidism with levothyroxine is usually simple, effective and safe, and most patients report improved well-being once they have started treatment. However medical professionals recognise that a proportion of individuals continue to suffer with symptoms despite apparently having thyroid function tests falling within the normal range.

For patients who have clearly not derived benefit from L-T4, endocrinologists (thyroid specialists) sometimes decide to begin a trial of L-T4/L-T3 combination therapy. Such patients should be supervised by accredited endocrinologists after a fully informed and understood discussion of the risks and potential adverse consequences.

We are aware that a number of patients have been advised by their GPs that L-T3 is no longer available for the treatment of hypothyroidism and that they should use L-T4 as an alternative treatment. We understand that this is as a direct result of the sharp increase in price of L-T3, which the NHS does not believe is sustainable. The sudden non-availability of L-T3 has caused considerable concern and we therefore feel that some clear advice would be helpful. The BTA has produced a similar FAQ fact sheet for GPs: [http://www.british-thyroid-association.org/sandbox/bta2016/faq_for_gps.pdf](http://www.british-thyroid-association.org/sandbox/bta2016/faq_for_gps.pdf) that you can print off and take with you to an appointment if you believe it would be useful.

What is the BTA and the BTF’s position as regards the withdrawal of L-T3 therapy?

The BTA and BTF believe that clinical need should come before financial considerations and they therefore do not support the practice of sudden withdrawal of L-T3 therapy. Patients established on L-T3 who continue to derive benefit from its use should continue to use it. However, patients with uncertain benefits should be considered for a switch to L-T4 and advice should be sought on how this can be safely done.

I have been on liothyronine (L-T3) a long time. Is there any problem with switching me to levothyroxine (L-T4)?

Your doctor should have made you aware of the risk to your thyroid stability. A change in treatment can unfortunately result in a significant instability in thyroid status, which can take some time to address.

Is there a resource to which I can refer with regard to the use of liothyronine (L-T3)?


This summarises the evidence for the use of liothyronine and states that we have yet to see conclusive evidence regarding its efficacy for this condition. Combination treatments of liothyronine and levothyroxine should be started and supervised by an accredited endocrinologist rather than a GP.

Is there any problem in switching to levothyroxine alone from combined liothyronine (L-T3)/levothyroxine (L-T4), or from liothyronine?

This has to be made gradually with the aim of avoiding under- or over-replacement. The final L-T4 requirement is likely to be around 1.6 mcg/kg. If there is any information about a previous L-T4 dosage that achieved a normal TSH this will be a useful guide. Gradual reduction of L-T3 starting at the same time as introducing L-T4 may be a preferable alternative. Careful monitoring of the patient during the transition period is essential.

Can I be switched from liothyronine (L-T3) to levthyroxine (L-T4) if I have been diagnosed with thyroid cancer?

Switching from L-T4 to L-T3 is part of a standard protocol used in patients with a history of thyroid cancer in preparation for radioiodine ablation, radioiodine therapy, iodine scanning or stimulated thyroglobulin test, so access to L-T3 is imperative.

Are there any particular patients who merit extra caution?

If you are over the age of 60, or have known heart disease, additional care is required to avoid over-replacement with L-T4/L-T3 combination therapy or L-T3 only therapy. If you are pregnant, L-T4/L-T3 combination therapy or L-T3 only therapy, are not recommended.

What is your advice concerning the use of desiccated animal thyroid extracts?

This issue is addressed in the 2015 BTA Statement on the Management of Primary Hypothyroidism. These thyroid hormone preparations are not currently recommended in the management of hypothyroidism.
which involved running, carrying, crawling, climbing and trekking but with added mental challenges and sleep deprivation for 60 continuous hours!

Zoe Haden ran the Cardiff Half Marathon in October and raised £350.

Sarah Houghton Carr and her daughter Cicely, who has an under-active thyroid, decorated a tree with BTF logos in their local Alverstoke Christmas Tree Festival to raise awareness.

Catherine Harper who has an under-active thyroid zip-wired from the Tyne Bridge in Newcastle for the BTF in October to mark her thirtieth birthday and raised over £100.

Virgin London Marathon 2017

We secured our first official charity place in the marathon this year and our chosen runner is David Swan.

‘Hi, my name is David and I work for a civil engineering contractor. I am very fortunate to be preparing to run the London Marathon 2017 on behalf of such a worthy charity, the BTF. My wife and father-in-law both have an under-active thyroid. I have run a number of 10k races before (44 minutes personal best) but never a marathon. The training has started and my long runs are underway with my goal being to achieve about 40 training miles per week. My wife who successfully completed the Chester Marathon in 2016 inspired me. So far, sponsors have been very generous with their donations, which is great news. I will be pleased with a sub four hour time – let’s see on the 23 April 2017!’

http://uk.virginmoneygiving.com/David_Swan

Donations

Many thanks for your generous donations. We are grateful for them all, including those donated online, often in response to advice and support from our telephone contacts, local coordinators and BTF head office and also for donations by members at the time of joining BTF or at renewal time.

Projex Building Solutions Ltd donated £500 in lieu of sending out Christmas cards to clients.

Future Fundraisers

Gavin Raby is running the Silverstone Half Marathon next March. He is keen to raise awareness of thyroid disorders as his wife has been diagnosed with thyroid eye disease.

www.justgiving.com/fundraising/Gavin-Raby

We have two runners taking part in the Vitality Bath Half Marathon in March:

Charlotte Kerr, who has several family members with thyroid problems and Eleanor James, who has an under-active thyroid.

www.justgiving.com/fundraising/EleanorJames2017

www.justgiving.com/fundraising/Charlotte-Kerr4

Bethan Howard Jones is taking on the Affric Kintail Trek, a new 44-mile cross-country route in Scotland in 24 hours in June. She has suffered from both an under-active and over-active thyroid and wants to raise awareness of the BTF.

www.justgiving.com/fundraising/BethanJayne

Tracy Gray, whose husband and daughter both have thyroid disorders, is running the Fleet Half Marathon in March with her sister and cousin.

www.justgiving.com/fundraising/T-Gray

Hayley Montgomery who has Hashimoto’s has won a local competition for a free entry to the St David’s day run (10k) in March and eight weeks of training with the British Military Fitness Team. Helen said: ‘As part of my video entry to the competition I had to explain who my chosen charity would be and why. Having had a personal insight into how supportive the BTF is and how much important research and development work is done each year, I was keen to help in some way’.

www.justgiving.com/fundraising/Hayley-Montgomery1

http://uk.virginmoneygiving.com/David_Swan
My Story

Me, myself and thyroid: 10 years with hypothyroidism

Chris was diagnosed with hypothyroidism 10 years ago. He explains how isolating it can be especially as a man with what is often considered a ‘woman’s condition’.

For a quarter of my life I have had a secret. A condition I very rarely talk about and which almost no one, including friends and family, is aware that I have - hypothyroidism. It’s not something many men my age suffer from, so there is no one I know that I can directly relate to and no one I feel I can discuss it with other than medical professionals.

My story began nearly 10 years ago after a blood test following a bout of irritable bowel syndrome. My TSH levels were high and I was put on levothyroxine as a preventative measure.

Physically I’m OK, and I recently managed a half-marathon raising funds for the BTF, but mentally I do struggle a bit. I find it hard to concentrate for any prolonged period, it takes me longer to do things than it used to, I’m often irritable and my memory is increasingly poor. I try to compensate by writing myself lots of notes and my work colleagues think I’m extremely conscientious and thorough. If only they knew it was because I’d forget half the things I was told if I didn’t write them down. And that’s the hardest bit really, as I used to have a good memory.

I’ve lost count of how many times I’ve had my levothyroxine changed over the years (currently 150 mcg) and I’ve had tests for diabetes, gluten intolerance and a few other things besides along the way. All come back negative. And yet I still don’t feel that well. I get told my thyroid results are within the ‘normal’ range and generally the response from GPs to my symptoms is to adjust my dosage a little bit, even though I don’t think it will make much of a difference.

So I try and persevere, working long hours to compensate for my shortcomings. I have a young family to support and don’t have time to feel too sorry for myself. And I know there are many people less fortunate than me.

And thankfully there are some good days too where the fog seems to lift and I can think clearly. On those days my outlook brightens and I feel happier and more ‘normal’ again. I try to make the most of these.

I take each day as it comes, good or bad and try not to look too far ahead, as my future self concerns me a bit. I don’t like the prospect of not being capable of doing things or having to rely on others. I’ve always tried to be self-sufficient and I want my daughters to be proud of their dad and I want to be there for them in the future.

But as I approach both a decade of being ill and my 40th birthday, perhaps the best thing for me is to no longer bottle everything up. To tell people I’m ill and maybe just having some support or even someone to share my thoughts and feelings with might just help me feel a bit better. And by writing this I already do!

Why is hypothyroidism less common in men?

Hypothyroidism is about eight to 10 times less common in men. This is because 80 per cent of hypothyroidism is caused by autoimmune disease, and autoimmune diseases are more common in women although nobody really knows why.

An autoimmune disease happens when your body’s immune system mistakes normal parts of your body for foreign invaders and attacks them. The autoimmune disease that usually causes hypothyroidism in women and men is Hashimoto’s thyroiditis. In Hashimoto’s, your immune system attacks your thyroid gland.

Other causes of hypothyroidism in men include damage to the thyroid or removal of the thyroid during surgery for thyroid tumours and treatments for an over-active thyroid that result in an under-active thyroid.

Graves’ disease is a cause of hyperthyroidism that may require treatments that leave a person with hypothyroidism. Graves’ disease is also more common in women.

Thank you Chris for running the Great North Run in September and raising nearly £800!

If Chris’s story resonates with you and you would like to talk to someone who has or has had a thyroid disorder for support and advice, we have a list of telephone contacts, along with which thyroid disorders they have experienced on the back page of every newsletter.
Vitamin D and thyroid disease

What is vitamin D?
Vitamin D is an important factor for overall health particularly strong and healthy bones. It is also a vital player in ensuring that a number of important organs such as muscles, heart, lungs and brain work well and the immune system is fit to fight against infections.

The body can make its own vitamin D from sunlight. However, adequate vitamin D can also be obtained from supplements and a small amount comes from a few foods. Vitamin D has to be changed by the body a number of times before it can be used.

What does vitamin D do?
Vitamin D is different from other vitamins. While the human body is dependent on various foods for adequate intake of these other vitamins, the body can make its own vitamin D from exposure of skin to sunlight. When the body gets its vitamin D, it turns the vitamin D into a hormone called activated vitamin D or calcitrol. Vitamin D is very important for strong bones and is required to absorb minerals such as calcium and phosphorus. Without enough vitamin D, these minerals cannot be absorbed into the body. Vitamin D is important for general good health, and now researchers are discovering that it may be important for many other reasons outside of good bone health. Some of the functions of the body that vitamin D has been linked with include:

- Immune system
- Muscle function
- Healthy heart and circulation
- Healthy lungs and airways
- Brain development
- Anti-cancer effects

Doctors are still working to fully understand how vitamin D works within the body and how it affects overall health.

How much vitamin D is needed?
Getting the right amount of vitamin D does not depend on the foods you eat. To get enough vitamin D you need to expose your skin to sunlight regularly and you may also need to take supplements. This makes getting the right amount a little more complex compared to other vitamins and minerals. Public health advice to avoid prolonged sun exposure and to wear sunscreen to protect against skin cancer – whilst scientifically sound to reduce risk of skin damage due to ultraviolet rays – has meant that there is some level of unnecessary alarm. A few minutes of skin exposure to sunlight without the use of sunscreen is safe and helps to generate adequate vitamin D levels. Various organisations recommend different daily requirements for vitamin D, ranging from 200 to 1000 IU (International Units) per day. This can vary depending on the colour of the skin, season, geographical location, and clothing.

Has vitamin D deficiency led to health problems?
Vitamin D deficiency has been linked to various diseases including osteoporosis, heart disease, some cancers, autoimmune conditions and poor muscle strength. The evidence to convincingly confirm a definite role for vitamin D deficiency in causing these various conditions is lacking however. The strongest proof about low vitamin D exists for osteoporosis and hence supplementation along with calcium is now routinely prescribed in this condition.

Does vitamin D or its deficiency have a role in the development of thyroid diseases?
Some, but not all, observational studies have found low blood levels of vitamin D in patients with hypothyroidism (under-active thyroid) as well as hyperthyroidism (over-active thyroid) due to Graves’ disease. It is not clear from these studies if low vitamin D is a cause, a consequence or an innocent bystander in the development of these common thyroid conditions. It is possible that low vitamin D may permit the under-performing immune system to facilitate progression of thyroid disease. Equally, it is also possible that people with thyroid diseases may have altered health or lifestyle that leads to a low vitamin D state. For example, patients with an over-active thyroid due to Graves’ disease may increase the breakdown of vitamin D into inactive products, whereas those with under-active thyroid may spend less time outdoors due to tiredness and thus have reduced sun exposure. Only properly conducted scientific trials will be able to answer this question in a definitive manner.

Is there previous evidence to link vitamin D deficiency in other autoimmune conditions and to show that supplementation may be beneficial?

Type 1 diabetes mellitus: Researchers in Finland observed that the accelerated increase in occurrence of autoimmune type 1 diabetes has stopped from 2006. They state that the otherwise unexplained 5-fold increase in the incidence of type 1 diabetes prior to 2006 was associated with a corresponding reduction in the recommended dose of vitamin D to one tenth since the 1950s. Since 2003, there has been a vitamin D fortification programme of milk and dairy products in Finland. In a separate observation, researchers found that there was an inverse association between new episodes of insulin-requiring diabetes and levels of serum vitamin D. However, trials of vitamin D supplementation in type 1 diabetes have shown conflicting results.

Multiple sclerosis (MS): Living below 35° latitude for the first 10 years of life reduces the risk of multiple sclerosis by approximately 50%. Among white men and women, the risk of multiple sclerosis decreased by 41% for corresponding increases in blood vitamin D levels. Women who ingested more than 400 IU of vitamin D per day had a 42% reduced risk of developing multiple sclerosis. Recently, in an observational study of 468 MS patients, higher serum vitamin D levels were associated with reduced disease activity and progression. Trials of vitamin D in patients with MS have shown that while some blood and MRI scan abnormalities improve this has yet to be translated into clinically meaningful results.

Should everyone be taking vitamin D supplements?
Most people’s skin will produce vitamin D in the summer but around a fifth of the population will still be deficient during this period. The situation is likely to be worse over winter. As it is not routinely possible to identify these individuals without everyone having a blood test, Public Health England has recently recommended that everyone over four years of age should take a low dose of vitamin D (400 IU), particularly in the winter and autumn months. The long-term health and economic effectiveness of this strategy is unknown at present.

By Dr Salman Razvi, Clinical Senior Lecturer/Consultant, Institute of Genetic Medicine, International Centre for Life, Newcastle University.
Did you know that thyroid problems could be regarded as disabilities?

The Equality Act 2010 sets out the circumstances in which a person is defined as ‘disabled’. It says someone is disabled if they have:

’a physical or mental impairment that has a substantial and long term negative effect on your ability to do normal daily activities’

By substantial they mean more than minor or trivial. For example it takes much longer than it usually would to complete a daily task.

By long term it means that it has lasted for 12 months or is likely to last for more than 12 months or for the rest of their life.

To be clear then it is not the thyroid problems themselves that count but how the condition affects you at work.

As lethargy and listlessness are often two symptoms connected with hypothyroidism some employers may mistakenly suspect you are feigning illness.

At any short-term sickness absence reviews your manager may ask the following:
Do you think your attendance problem is related to your condition?
Are you fully compliant with your medication?
Do you fully understand what your condition is?
Would you like to have a chat with an occupational health consultant?

Ultimately treatment should reduce any symptoms but until your dosage is correct – and this can take a while – hypothyroidism can cause difficulties such as extreme tiredness, memory problems and concentration challenges. As a consequence you may struggle with analysis of figures; with handling large amounts of paperwork; with doing night shifts; with undertaking a lot of driving and so forth.

Thyroid hormone replacement is life-long and falls within the definition of the Equality Act 2010 as without thyroid hormone replacement the hypothyroidism is likely to recur. Hypothyroidism can be adequately replaced in the long term with levothyroxine and hormone replacement is not associated with any significant increased morbidity or mortality provided that a therapeutic target is reached. Without thyroid hormone replacement the impact of the disability would substantially limit the ability to carry out normal day-to-day activities. However, adequate treatment should prevent any symptoms related to the disability from this point onwards.

Under the Act your employer must take steps to activate their duty and give serious consideration to your individual needs as a disabled person. They must also make reasonable adjustments to the way in which you are employed in order to accommodate those needs.

Taken from Dr Mark Vanderpump’s blog
www.markvanderpump.co.uk/blog

The Evelyn Ashley Smith Nurse Award

Evelyn Ashley Smith was a member of the BTF for many years. She made this award available to improve the care provided to patients with thyroid disorders.

The BTF is offering two awards of up to £500 to help cover conference/training expenses, including registration fees and/or travel costs.

Who can apply?

Endocrine nurses, nurses, midwives and healthcare professionals working in the UK. Trustees of the BTF may not apply for this research award. Information about previous awards granted is available at http://www.btf-thyroid.org/professionals/nurse-award

How to apply

Please complete the application form at www.btf-thyroid.org/professionals/nurse-award/180-nurse-award-application and email it to nurse-award@btf-thyroid.org by midnight 1 July 2017.
**Fight for Sight/British Thyroid Foundation/Thyroid Eye Disease Charitable Trust Small Grant Award 2013 final report**

Dr Matt Edmunds, University of Birmingham, the winner of this award, outlines his research and findings on Digital Infrared Thermal Imaging for Early Diagnosis and Disease Monitoring in Thyroid Eye Disease below:

‘We used a thermal imaging camera to take specialised photographs, measuring the temperature of the tissues around the eyes, in patients with a thyroid condition in which the immune system becomes over-active (Graves’ disease).

‘Around a quarter of those with Graves’ disease can go on to develop eye problems, with bulging eyes, redness and swelling, grittiness, soreness and pain, double vision and even blindness, known as Thyroid Eye Disease (TED).

Unfortunately, it is currently impossible to predict which Graves’ patients will develop TED and the existing methods for assessing patients are sometimes inaccurate and prone to misinterpretation. We found three main important features in our thermal imaging analyses:

1. As a group, those with Graves’ disease, even without the outward appearance of TED, had higher eye tissue temperatures than healthy people without any medical problems. This supports the existing medical evidence that tells us that around 70% of Graves’ patients without TED will have abnormalities on scans (e.g. CT or MRI) of their eye sockets.

2. It was possible to detect early signs of inflammation, as shown by an increase in temperature around the eyes on thermal imaging photography, in Graves’ disease patients going on to develop TED. This raises the possibility of making a diagnosis of TED at the earliest possible stage and therefore intervening with therapies before the unpleasant effects of TED take place.

3. We were able to track temperature increases as Graves’ patients developed worsening TED, and then track a normalisation of temperature as the disease became inactive. This is important as this may permit us to make more accurate decisions about whether patients have worsening TED (and require treatment to control the over-active immune system) or stable TED (and may be at the point in their disease course where they can have surgery to improve their physical appearance and how their eyes function).

We hope that the technique of thermal imaging may be used alongside our skills of clinical assessment to aid in the early diagnosis and monitoring of patients with Graves’ disease and TED, particularly in decision-making about the timing and types of treatments that may be used.’

Presentations of Dr Edmunds’ work have won two prizes - The Ian Fraser Cup for best clinical research oral presentation at the Oxford Ophthalmological Congress, July 2016 and first prize for his poster at the European Society of Ophthalmic Plastic and Reconstructive Surgery (ESOPRS) Annual Meeting, Athens, September 2016.

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**Doris Godfrey Research Award 2016 interim report**

Simon Pearce, Professor of Endocrinology and Honorary Consultant Endocrinologist, Institute of Genetic Medicine, International Centre for Life, Newcastle upon Tyne and Chief Investigator Dr Petros Perros have provided an interim report of their studies so far on Differentiated thyroid cancer survival, recurrence rates by disease stage and quality of life in the Northern Cancer Network

**Introduction**

This project aims to ascertain 10-year survival and recurrence rates in patients with thyroid cancer, classified by disease stage. Although data on the incidence of thyroid cancer and mortality are collected in the UK, they are not available by disease stage. This is a crucial omission if we are to understand how successful our treatments are year after year and how we compare with other developed countries.

So far we have ascertained disease status and 10 year survival in 47 patients. There were 21 patients with stage I disease, 15 with stage II, 1 with stage III, 4 with stage IVA and 1 with stage IV.

**Ten year survival**

Forty-three of 47 patients survived 10 years after diagnosis. Three of these deaths were unrelated to thyroid cancer. The single death from thyroid cancer was aged 50 at the time of diagnosis, female and had stage IVA disease with papillary thyroid cancer and tall cell elements. She died of pulmonary and cerebral metastases. So the overall disease specific 10 year survival was 96%.

**Recurrence rates**

Recurrences were noted in three patients, one with stage I, and 2 with stage IVA disease. Excluding patients who died, the overall recurrence rate was 6.9% at 10 years.

**Other cancers**

Four patients who survived 10 years had another cancer diagnosis. Three developed it after the diagnosis of thyroid cancer (two breast, one lymphoma) and one had been treated for acute lymphocytic leukaemia three years before the diagnosis of thyroid cancer.

**Comment**

These figures are very preliminary and represent a small number treated in our centre. As expected the majority of cases had low risk thyroid cancer (44.7% had stage I disease). However, so far the disease-specific 10 year mortality is extremely low at 2% and in contrast to the high mortality quoted by Eurocare-4 (a Europe-wide database on cancer survival) for England (19.5% five year mortality compared to other European countries e.g. Iceland 96%). One possible explanation for this discrepancy is that the Eurocare-4 data did not report survival based on disease stage, and it is probable that the UK registered data are heavily biased towards advanced thyroid cancers.

Progress has been slow due to the lengthy procedures that need to be observed in obtaining data from the National Cancer Intelligence Network, but so far the data are encouraging and at least this is proof that it is possible to collect such data.
Letters and Comments

We welcome letters from our members but please note that letters may be edited at the Editor’s discretion.

Please address general letters to: The Editor, BTF News, The British Thyroid Foundation, Suite 12, One Sceptre House, Hornbeam Square North, Hornbeam Park, Harrogate HG2 8PB or by email to editorialboard@btf-thyroid.org

Please address medical queries to the Medical Enquiries Coordinator at the address above or by email to medical-query@btf-thyroid.org. Please remember to include your membership number.

Unless you state otherwise, we will assume that you consent to having your letter and our reply published in the newsletter. Medical queries will be anonymised. Medical questions, whether or not intended for publication, will normally be referred to one of our medical advisors, and you will receive a confidential reply. Please note that our advisors are not able to give you a written personal consultation and that their advice is provided for information only. For specific medical queries you should make an appointment with your doctor. You should not alter the recommended treatment issued by your personal physician without their knowledge and agreement.

Thyroid function test reference ranges

JB asks: I recently found your website and would like to request some additional information regarding thyroid conditions and testing. Please could you confirm the following? Your website states measurement of TSH, FT3 and FT4 as key factors in determining whether an individual may have a dysfunctional thyroid gland. The website also goes on to provide typical ranges within which the TSH, FT3 and FT4 should fall in order to be classified as ‘normal’ or ‘dysfunctional’. I would like to know whether (aside from the listed variation) there is any permissible scope for variation (and if so by how much) in typical TSH, FT3 and FT4 levels which could be considered ‘normal variation’ (attributable to whatever cause), and therefore not an issue to be overly concerned about. I would also like to know – if an individual was concerned about whether their thyroid function was abnormal – aside from consulting their GP, whether there may be any alternative methods or resources by which that individual could gain a second opinion or diagnosis.

Our medical advisor replies: The thyroid function tests (TSH, FT3 and FT4) are the best way of assessing normal, over- or under-activity of the thyroid. The reference ranges given are typical but individual labs and individual assay methods by the various labs may provide their own ranges. Minor variations either side of the reference range may be accepted as normal depending on the clinical context. There may be other factors such as antibodies which may interfere with the test method and give a different result. The labs have strategies to deal with these such as testing in dilution or by an alternate method. Your GP would be your primary source of interpreting the thyroid function tests requested from the local lab. If a second opinion is needed to this, a referral to an endocrinologist – NHS or private – may be sought.

High anxiety – could it be a thyroid problem?

MO asks: My daughter developed a large goitre in about May this year and developed severe anxiety at the same time. She has gone from being a straight ‘A’ student to a girl I can’t get to school and has given up all her sporting activities – running, gymnastics, netball to name a few. Her thyroid function came back normal but hospital bloods show antibodies. She has had a scan a few weeks ago and we are still waiting on those results. Her GP keeps saying it’s her mental health, but knowing my daughter I disagree. We lost her dad – my husband four years ago, but up until the goitre appeared she was fine. Now she has anxiety, frequent bowel movement, pain under both ribs, no period for three weeks and I am also waiting for thyroid bloods to come back. Please can you advise her GP about the estrofem as I saw it might interfere with levothyroxine. My normal dose is usually 30%. I am due to see an endocrinologist in a few weeks and I am also waiting for thyroid bloods to come back. Please can you advise her GP about the estrofem as I saw it might interfere with levothyroxine.

Our medical advisor replies: The thyroid function tests (TSH, FT3 and FT4) are the best way of assessing normal, over- or under-activity of the thyroid. The reference ranges given are typical but individual labs and individual assay methods by the various labs may provide their own ranges. Minor variations either side of the reference range may be accepted as normal depending on the clinical context. There may be other factors such as antibodies which may interfere with the test method and give a different result. The labs have strategies to deal with these such as testing in dilution or by an alternate method. Your GP would be your primary source of interpreting the thyroid function tests requested from the local lab. If a second opinion is needed to this, a referral to an endocrinologist – NHS or private – may be sought.

Can I take hormone tablets and levothyroxine together during pregnancy?

JC asks: Hello, I have recently become pregnant through IVF. I am three weeks along. I have been told to continue with estrogen oestrogen tablets three times a day along with progesterone to support the pregnancy in the first trimester. I have increased my levothyroxine by 25 mcg as I read that you need to increase by around 30%. I am due to see an endocrinologist in a few weeks and I am also waiting for thyroid bloods to come back. Please can you advise about the estrofem as I saw it might interfere with levothyroxine. My normal dose is usually 50 mcg but I have increased to 75 mcg.

Our medical advisor replies: Increasing the dose of levothyroxine to 75 mcg is the correct thing to do whilst you await thyroid function tests results. I would suggest that...
you take levothyroxine first thing on an empty stomach with some water and that you don’t take anything else with this and that you don’t eat or drink (including tea or coffee) for at least 30 minutes – you probably know this and take the medication in this manner anyway. I think the interference from oestrogen will be minimal and your thyroid function tests will be monitored so the doses can be adjusted if needed. In any case the oestrogen and progesterone treatment is likely to be for a short period of time. All the best with your pregnancy.

Levothyroxine and dry eyes

BW asks: My daughter was treated for papillary thyroid cancer in 2002 at 20 years old. She takes 200 mcg levothyroxine which as a retired ophthalmologist I think is the cause of her dry eyes. Does anyone else in the BTF have the same view? All her blood tests are satisfactory and her oncologist does not think there is an association.

Our medical advisor replies: A significant proportion of patients who have had thyroid cancer have Hashimoto’s. There is an association between Hashimoto’s and dry eyes. Also if your daughter had radioiodine as part of her treatment for thyroid cancer that can cause dry eyes. There is a direct link between levothyroxine use and dry eyes.

You are probably already aware of eye lubricants that might help - an eye lubricant such as Optive Fusion or Clinitas Multi, which is preservative free, may be worth trying.

Link between thyroid disorders and type 1 diabetes?

AL asked: Is there a link between type 1 diabetes (which I have had for a long time) and a thyroid disorder, which was diagnosed five weeks ago? My blood sugar levels have gone sky high and I want to know if there is a link and if so what can I do about it?

Our medical advisor replies Patients with type 1 diabetes are more likely to develop problems with the thyroid, mostly under-active thyroid problems. If this is not detected and treated it may interfere with the control of the diabetes in some cases. Treatment of thyroid disorders in patients with diabetes is essentially the same as in those without diabetes. So you should get your thyroid treated and then see your doctor to control the diabetes.

Radioiodine treatment success outcome

JA asks: My 21 year old son is due to have radioiodine treatment following 18 months on propylthiouracil (PTU) which was unsuccessful. He’s back on the PTU to stabilise his thyroid level. Having listened to patients’ experience of radioactive therapy from the video on your website I would like to know if iodine treatment always completely destroys the thyroid and will he need levothyroxine for life or can a part of the thyroid still function?

Our medical advisor replies: Hypothyroidism would be expected to occur in between 70-90% of patients who receive outpatient radioiodine therapy for Graves’ hyperthyroidism. This is therefore the expected outcome and once hypothyroid he will need levothyroxine for life. There can be some variability based on the size of the thyroid gland, iodine status and the amount of iodine absorbed but the dose chosen in most centres aims to achieve cure with this range of potential hypothyroidism. Lower doses would lead to a higher chance of recurrent hyperthyroidism in the early years with a significant proportion developing future hypothyroidism.

Levothyroxine queries – OK to switch brands and take at night?

ST asks: I take 75 mcg of levothyroxine each day. I’m told that the manufacturers do not do a 75 mcg pill so I take a 25 mcg and 50 mcg. Each month my pharmacy supplies these pills but they are often different brands and the next month I will be given two lots of yet other different brands. Over the last three months for example I have taken five different brands. Does this matter? I mention this because I think I do feel different. I used to live in France and there they only use one manufacturer so this issue did not arise.

My second query concerns the time of day to take the medication. At the moment I take it first thing in the morning before breakfast. But there is not always a half hour gap between taking the pills and eating breakfast. It is difficult for me to achieve this. So could I take the medication at another time of day when eating isn’t an issue? I was thinking about at night, immediately before I go to sleep?

Our medical advisor replies In respect of your question about levothyroxine brands, doctors tell us that it is very rare that different brands should make a difference but we do know from patients who contact us that it can happen. You will be pleased to know that Teva have recently launched a new formulation of levothyroxine (see page 5) which is available in new strengths (12.5, 25, 50, 75 and 100 mcg) so you should ask your doctor to request these for you so that you can consistently use the same brand.

The tablets should ideally be taken at the same time each day on an empty stomach and at least an hour before food. Many people find the most convenient time is last thing at night, as you suggested. This would be fine.
Unity Lottery

Play the Unity Lottery and win up to £25,000 and many more prizes every week!

Directly supporting the British Thyroid Foundation, Unity is a lottery with a difference. We receive profits directly from the number of lottery players we recruit, so we need your support. For every £1 entry, 50p comes directly to the BTF as profit.

How it works

For just £1 per week you will be allocated a six digit Unity lottery number. You can purchase more than one entry if you wish. Every Saturday, the lucky winners are selected at random and the prize cheques issued and posted directly to you, so there is no need for you to claim. You must be 16 over to enter. Winners have to match 3, 4, 5 or all 6 digits of the winning number in the correct place in the sequence.

To join go to: www.btf-thyroid.org/support-us/3-play-the-btf-lottery

Directly support the BTF by playing the Unity lottery and be in with the chance of winning £25,000!

Win up to £25,000

Help support the BTF

PRIZES

£25,000
6 digits

£1000
5 digits

£25
4 digits

£5
3 digits

JustTextGiving from Vodafone

You can support people with thyroid disorders by donating via your mobile phone. Just text THYR01 and the amount you would like to donate to 70070.
Local Groups

Please check the BTF website (www.btf-thyroid.org) for the latest details. Please also check before you attend a meeting that it has not had to be cancelled due to poor weather conditions.

Birmingham
Next meeting: TBA. Check the BTF website for further details.
Location: TBA
Programme: TBA
Contact: Janet Tel: 0121 628 7435 or email: janetdmp@googlemail.com

Bristol
Next meeting: Michelle is forming a new group in Bristol. Email her at Michelle.Griffiths@hotmail.co.uk if you would like more information.

Cambridge
Next meeting: Saturday 20 May 2017 10am to 12-30pm.
Location: Hills Road Sixth Form College, Cambridge CB2 8PE.
Programme: Dr Mark Vanderpump, President of the BTA and BTF Trustee will talk about the BTA/BTF hypothyroid guidelines.
Contact: Mary on 01223 290263 or email butterflyecho@hotmail.com

Edinburgh
Next meeting: The Edinburgh BTF Support Group meets on the last Tuesday of the month except for school holidays. Check the BTF website for further details.
Location: Liberton High School, Gilmerton Road, Edinburg, EH17 7PT.
Contact: Margaret Tel: 0131 664 7223 or email: M2mcgregor@aol.com

Leeds (Wharfedale)
Next meeting: TBA. Check the BTF website for further details.
Location: TBA
Programme: TBA
Contact: Caroline on 0113 288 6393 or email: cfields237@btinternet.com

London
Next meeting: Saturday 11 March 2017 10am to 1pm.
Location: Crown Court Church, Russell Street, Covent Garden, London WC2B 5EZ. http://www.crowncourtchurch.org.uk/where-to-find-us/
Programme: This will be a support group meeting. In order to continue, the group needs more volunteers to help run it - email if you can help.
Contact: londonthyroid@gmail.com

Milton Keynes
Next meeting: Saturday 4 March 2017 10.30am to 1pm.
Location: The Pavilion, Open University, Milton Keynes, MK7 6AA.
Programme: Whether you are newly diagnosed or have a long-standing thyroid condition come and join our local meetings. Our information events are held regularly with professional and informative speakers. They provide an opportunity to meet with others who have a thyroid condition. We always have professional speakers with a health related background. They are usually drawn from the local hospital and community health services.
Future meetings: Saturday 1 July 2017, Saturday 7 October 2017.
Contact: Wilma Tel: 01908 330290 or see http://www.thyroidmk.co.uk or find us on Facebook.

Start a support group!

Are you interested in bringing people together to start a BTF support group in your area? We would particularly like to set up new groups in the North East, North West and South coast. Email info@btf-thyroid.org

Buy a teddy and support the BTF

Buy one of these adorable teddies for £7.50 and all the profit will go towards the BTF.

Go to http://www.btf-thyroid.org/support-us/awareness-merchandise to order online.

Support for thyroid patients online

We have successful Facebook groups for hyperthyroidism, parents of children with thyroid disorders, thyroid eye disease and thyroid cancer that you can join and share experiences and information. (These are ‘closed’ groups for approved members and only group members can see posted content.) To join, go to Facebook, search for the group you would like to become a member of and send a request. (You will need a basic Facebook profile.) Alternatively email info@btf-thyroid.org with the name of the group you would like to join and your reasons for joining.

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Our voluntary local coordinators organise meetings but will also be happy to take calls on thyroid disorders that they have experienced. Please see the key below.

**BTF LOCAL COORDINATORS**

**Birmingham**
Janet (PC,CS,RAI,PH) 0121 6287435
janetdmp@googlemail.com

**Leeds (Wharfedale)**
Caroline (O,U) 0113 2886393

**Cambridge**
Mary (O,RI,U) 01223 290263
butterflyecho@hotmail.com

**London**
Caroline (PC,CS,RAI,PH) 020 8735 9966
Gay (G,TS) 020 8735 9966

**Edinburgh**
Margaret (PC) 0131 6647223

**Milton Keynes**
Wilma (U) 01908 330290

**BTF TELEPHONE SUPPORT CONTACTS**

Our telephone contact volunteers are happy to take calls on thyroid disorders that they have experienced. Please see the key below.

**Dave (PC,CS,RAI)** 07939 236313
**Colin (O,RI,U)** 07973 861225

**Jackie (PC,CS)** 01344 621836
**Olwen (O,RI,U)** 01536 513748

**Gay (G,TS)** 020 8735 9966
**Jane (GR,RI,TED,G,U)** 01737 352536

**Welma (U)** 01592 754688
**Peter (TED,GR)** 01200 429145

**Angelina (U)** 01943 873427
**Penny (Ch)** 01225 421348

**Maria (U)** 020 87934360

**KEY**

Ch  Thyroid disorders in children
C  Cancer of the thyroid
PC  Papillary cancer of the thyroid
CS  Thyroid cancer surgery
RAI  Radioactive iodine (I-131) ablation
G  Goitre
TS  Thyroid Surgery (non-cancer)
U  Under-active thyroid
O  Over-active thyroid
GR  Graves’ disease
RI  Radioactive iodine treatment for an over-active thyroid
TED  Thyroid eye disease
PH  Post-operative hypoparathyroidism

**OUR PARTNER ORGANISATIONS**

**AMEND**
The Association for Multiple Endocrine Neoplasia Disorders
Tel: 01892 516076  www.amend.org.uk

**Hypopara UK**
Helpline: 01342 316315  www.hypopara.org.uk

**Thyroid Cancer Support Group Wales**
Tel: 08450 092737  www.thyroidsupportwales.co.uk

**Thyroid Cancer Support Group Ireland**
email  info@thyroidcancersupport.ie  www.thyroidcancersupport.ie

**Butterfly Thyroid Cancer Trust**
Tel: 01207 545469  www.butterfly.org.uk

**Cancer52**  www.cancer52.org.uk

**Thyroid Cancer Support Group Wales**
Tel: 0131 6647223

**Thyroid Eye Disease Charitable Trust**
Tel: 07469 921782  www.tedct.org.uk

**British Thyroid Association**
www.british-thyroid-association.org

**British Association of Endocrine and Thyroid Surgeons**
www.baets.org.uk

**CURRENT MEMBERSHIP RATES**

**Members living in the UK**

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<th>By Standing Order</th>
<th>Lifetime Membership</th>
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**Members living overseas £25 (electronic newsletter only)**

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Concession: If you are retired you may wish to pay the concessionary rate. Please help us by ensuring that you pay the correct subscription.

**Places still available in the Morrisons Great North Run and Vitality British 10k London Run! Email fundraising@btf-thyroid.org for an application form.**