At ‘vet school’ we were often told ‘cats are not small dogs’ and this definitely applies to thyroid disease. I have never seen a hyperthyroid dog, and never seen a hypothyroid cat but the opposite conditions are extremely common.

In dogs hypothyroidism is usually caused by immune-mediated destruction of the gland, with less than 5% of cases caused by thyroid neoplasia, congenital disease or central nervous system disorders. Hypothyroidism is most common in middle aged dogs of either sex, with Dobermann Pinschers and Golden Retrievers having the highest incidence. As in people, dogs tend to be lethargic and gain weight. Changes in the skin are common, including a ‘tragic’ facial expression and a hairless ‘rat tail!’ They may also have symmetrical alopecia along their flanks. The disease tends to creep up on dogs, often owners do not realise how affected their pets have become until they are treated.

Diagnosis is by free T4 and TSH measurement and treatment is with levothyroxine. Dogs metabolize thyroxine much faster than humans with a half life of 9-15 hours instead of 6-10 days. Consequently, a dog requires a much larger dose: a Retriever needs 800mcg daily, whereas an adult human will typically need 125 mcg per day!

Hyperthyroidism in cats was first described in 1979 and is now the most common endocrine disorder. Risk factors have not been fully established but may be linked to chronic exposure to thyroid-disrupting chemicals in the environment. The disease has been likened to multinodular goitre in humans. Thyroid stimulating immunoglobulins responsible for Graves’ disease in humans, have not been identified in cats.

Hyperthyroidism is seen in older cats, with the average age of onset 12-13 years, and no apparent breed or sex differences. Often owners will remark how lively and energetic their old cat has become, along with weight loss despite a very good appetite. Cats will often try to seek out cool areas and their temperament can be described as ‘spiky.’ There is often an obvious goitre and an increased heart rate, over 240 beats per minute (normal is about 180 bpm).

Diagnosis is by free T4 measurement and treatment usually starts medically with 5mg carbimazole twice daily. Cats are notoriously difficult to ‘tablet’ so recently some alternative options have become available, such as a transdermal carbimazole gel to apply to the ear, or an iodine-deficient prescription diet. This, however, is not as easy as it sounds as the cat must not eat any other food or treats, or hunt wildlife, and other cats in the family must not eat this food!

Whilst medical treatment can continue for life, surgical thyroidectomy is considered gold standard. Postoperative complications of hypocalcaemia can occur if the parathyroid gland is damaged. Permanent hypothyroidism is rare so treatment with levothyroxine is not usually required. Radioactive iodine treatment is available in specialist centres, and requires the cat to be isolated for a few weeks because of the radiation risk.
Retirement of Director

It was a sad farewell to Janis Hickey as Director at her last trustees’ meeting, held in November 2017. The trustees presented Janis with a bouquet of flowers and thanked her for her dedication and hard work since setting up the BTF over twenty-five years ago. However, it is not a final farewell as Janis will be staying on to work on the Thyroid Eye Disease project and the iodine project, both of which are close to her heart.

In December, Janis attended the BTF office Christmas lunch. She was presented with a number of gifts, purchased through the kind contributions of BTF members, volunteers and medical advisers who have worked closely with Janis over the years. Janis would like to thank each and every one of them for their kindness. ‘Thank you so very much for your lovely messages, good wishes and retirement gifts – the handbag is beautiful! I will treasure them all’.

Welcome back Fiona!

We are delighted that Fiona Maxwell has returned to the BTF at HQ as an office volunteer. The BTF very much appreciates all the help she provides each week.

Welcome to the joint CEOs

The charity’s trustees are pleased to announce that as from January 2018 Julia Priestley and Cheryl McMullan began their new roles as joint CEOs of Development and Operations respectively. Julia says of her new role: ‘It’s a daunting prospect to be stepping into the shoes of someone like Janis as she has achieved so much for people affected by thyroid disease. I am looking forward to working with Cheryl, the staff and volunteers at BTF and together, we can build upon Janis’s impressive legacy as Director.’

Cheryl is equally excited about her new role. ‘I am so pleased to have this opportunity to further the aims of the organisation. Julia and I will continue to raise the profile of the charity, which in turn will help provide better support for patients with thyroid disorders. Although we will have very different roles, I am looking forward to working alongside Julia.’

BTF Christmas cards

The BTF sold Christmas cards again, between October to December 2017. We used a number of venues - St Peter’s Church, Harrogate, Harrogate Library and St Helen’s Church, York – and are grateful to each of these venues for offering this opportunity. We would like to thank all the volunteers who gave their time to help sell the cards, particularly on some very cold, frosty mornings! We very much appreciate all their thoughtfulness in supporting the BTF.

Thank you also to all our members and supporters who bought the cards and to those who made generous donations to help with the work we do. We raised over £1500 from card sales in 2017.

Farewell to….

Dr Tim Cheetham, who is stepping down as BTF Trustee due to other commitments. Tim has been a Trustee since 2015 and says that it’s with a heavy heart that he has to stand down but that it’s been an enjoyable experience and he’s learned a lot. Tim will be continuing as a BTF medical advisor.
Out and About

The autumn was a busy time for BTF staff and volunteers, attending meetings and representing the charity at conferences.

Oculoplastic Allied Health Professional Study Day

In September Cheryl McMullan, CEO (Operations), gave a talk at the 6th ‘Oculoplastic Allied Health Professional Study Day’ hosted by Moorfields Eye Hospital in London. Cheryl says: ‘I was delighted to be asked to present information and updates about the BTF’s activities.’ It was a packed programme of stimulating topics and speakers from various healthcare backgrounds. Mr Jimmy Uddin, Consultant Ophthalmologist, and Miss Rebecca Ford, Consultant Ophthalmologist and Chair of the Thyroid Eye Disease Charitable Trust (TEDct) were amongst the speakers.

British Association of Endocrine and Thyroid Surgeons meeting in Belfast

In October Julia Priestley, CEO (Development) represented the BTF at the British Association of Endocrine and Thyroid Surgeons (BAETS) in Belfast.

The meeting featured lectures covering many aspects of endocrine surgery, including the pathology and genetics of thyroid disease. The BTF is grateful to the BAETS committee who invited us to have an information stand at the event.

The Royal College of General Practitioners Annual Conference

BTF members have, for a long time, asked us to focus on developing closer contacts with GPs. With that in mind, the BTF was represented at the Royal College of General Practitioners Annual Conference in Liverpool in October.

The meeting provided an excellent opportunity to raise awareness about the BTF amongst doctors and nurses who work in primary care. It was also a chance to meet with representatives from other patient organisations. We were able to share ideas about innovative patient resources along with new and effective ways to engage with GPs.

British Endocrine Society meeting in Harrogate

In October, the annual British Endocrine Society meeting took place in Harrogate. The event was hosted by the Society for Endocrinology. The meeting was attended by over 1,000 delegates, speakers and exhibitors. The BTF was invited to have a stand at the conference and also to support a session about thyroid cancer.

This event provides an opportunity to develop the endocrine community and contribute to the recognition of endocrinology around the world.

A particular highlight this year was the launch by TEAMeD of the ‘TEAMeD-5’ campaign. The aim is to promote better care for patients who have, or are at risk from, thyroid eye disease. The launch was met with great enthusiasm. For more information about older people and thyroid disease see BTF News 95, pp 6-7.

The Royal College of General Practitioners Annual Conference

Royal College of General Practitioners Annual Conference

British Society of Paediatric Endocrinology and Diabetes

The annual meeting of the British Society for Paediatric Endocrinology and Diabetes was held in Newcastle in November. The BTF was invited to have an information stand at this important scientific meeting.

The Thyroid Symposium on day two of the meeting featured a talk by Dr Rachel Knowles. Dr Knowles is a Paediatric Epidemiologist and Consultant in public health medicine at University College London. She spoke about the results of her study of Congenital Hypothyroidism (CHT) (see Research News page 10).

Dr Catherine Peters, Consultant Paediatric Endocrinologist at Great Ormond Street Hospital (GOSH) gave a presentation about the management of CHT at her hospital.

The thyroid session ended with a fascinating talk by Dr Salman Razvi, Consultant Endocrinologist at Newcastle. Dr Razvi spoke about managing subclinical hypothyroidism (SCH) in adults and the lessons that might be applied when managing children. He explained that levothyroxine is now the most prescribed medication in the United States of America and the third most prescribed in the UK. The reasons for an increase in its use are not clear but may be linked to increased testing or increased screening.

One of Dr Razvi’s findings is that there does not appear to be significant benefits when prescribing levothyroxine to older patients with SCH. This is a conclusion shared by a number of studies. For more information about older people and thyroid disease see BTF News 95, pp 6-7.

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The BTF is currently focusing on several key thyroid-related areas with the aim of improving knowledge, assisting with research and improving the patient’s experience. We are developing strategies for hypothyroidism care, pregnancy, iodine deficiency and subsequent thyroid problems, children with thyroid issues, thyroid cancer and thyroid eye disease.

Iodine and Pregnancy

The writing group for the forthcoming Royal College of Obstetricians and Gynaecologists (RCOG) Green-top Guidelines for thyroid disease in pregnancy has nearly completed the first draft. The topics covered will be: thyroid function tests in pregnancy, iodine and supplementation in pregnancy, hypothyroidism in pregnancy, hyperthyroidism/thyrotoxicosis in pregnancy, thyroid antibodies and miscarriage and preterm delivery, thyroid nodules and thyroid cancer, postpartum thyroiditis, and screening for thyroid disease during pregnancy.

Children

In response to families and professionals the BTF Children’s Project group are preparing a resource for children and young people affected by thyroid disorders. To make it as relevant as possible we would like to include personal experiences and stories from the children who’ve grown up with thyroid disease. Thank you to all those who have been in touch so far. If your child or teenager would like to find out more about how they can contribute to this project please email Julia.priestley@btf-thyroid.org (subject: Children’s Resource)

The BTF is taking part in a project that seeks to improve the process by which newborn screening results are delivered. The project is called ‘Rethinking Strategies for Positive Newborn Screening Result Delivery (ReSPoND): a process evaluation of co-designing interventions to minimise impact on parental emotional well-being and stress’ and is being led by Dr Jane Chudleigh, Senior Lecturer at the Department of Child Health, City, University of London. This research was funded by the NIHR HS&DR Programme, project number 16/52/25.

The first meeting of the project steering committee took place in January. In addition to the research professionals there were representatives from other charities and patient organisations who support families affected by the conditions identified by the results of the newborn screening testing.

Thyroid cancer

Over the last year the BTF Cancer Group has made submissions in support of some of the new treatments used for patients with progressive, locally advanced or metastatic, differentiated (papillary/follicular/Hürthle cell) thyroid cancer, which is resistant to radioactive iodine.

We are pleased that in October the All Wales Medicines Strategy Group accepted lenvatinib (Lenvima®) for use within NHS Wales.

Thank you to all the patients and medical professionals who helped us with these submissions.

The Third Edition of Thyroid Cancer: For Patients, By Patients is now available to download free of charge from the BTF website.


NICE guideline on thyroid disease

The consultation on the draft scope of the guideline took place in the Autumn 2017 and a committee has now been appointed which will consider the suggestions and prepare the guidance. Thank you to all the BTF volunteers and patients who took the time to contribute to the consultation.

BTF supporting the Big Blind Walk

Julian Jackson lost his sight in 2010 to an inherited disease affecting his retina. Since then, he has overcome many challenges. His personal experiences have convinced him that ongoing eye research will provide the solutions for those wrestling with avoidable and unavoidable sight loss. In particular, these breakthroughs bring hope, independence, mobility, financial independence and emotional well being to the blind and partially sighted.

The BTF is delighted to be supporting Julian on his Big Blind Walk. This will take him 1,000 miles between Land’s End and John O’Groats. Julian has again decided to embark on an inspirational and courageous fundraising challenge to raise awareness of sight loss. The money raised will support research and create a translational research fund at the National Eye Research Centre (NERC). As a charity that support patients with Thyroid Eye Disease and promotes better treatment for patients, we are very proud to be a supporting organisation for Julian. We wish him all the luck with his remarkable fundraising efforts!

If you would like to sponsor this walk, help plan the route, drive the support vehicle, walk with Julian along some of the way, introduce him to potential sponsors or generate some media interest then please email julian@visionbridge.org.uk or telephone him on 07773 800073.

For more information please go to:
https://bigblindwalk.com/campaigns/the-bigblindwalk-cornwall/
Myths and misunderstandings about the thyroid

Julia Priestley, CEO (Development) writes about some of the commonly held myths and misunderstandings about the thyroid and thyroid disease.

Diagnosing hypothyroidism with a thermometer

About 50 patients are admitted to UK hospitals every year, usually in the winter months, with myxoedema coma. Usually these are elderly patients who are severely hypothyroid and become very sick and hypothermic. Their body temperature can be very low and unfortunately many do not survive.

The connection between body temperature and thyroid function is well known. One of the common symptoms of hypothyroidism is cold intolerance. Thyroid hormones are major regulators of metabolism and heat production by the body. It is alleged that the diagnosis of hypothyroidism can be made by measuring body temperature which, if less than 37 degrees Celsius (98.6 degrees Fahrenheit), can signify hypothyroidism, even though thyroid blood tests may be normal. This is referred to in some circles as ‘Wilson’s syndrome’ though the World Health Organisation International Classification of Diseases does not recognise the existence of this entity. The American Thyroid Association placed an article on its website in 2005 on this topic and concluded: ‘The American Thyroid Association has found no scientific evidence supporting the existence of ‘Wilson’s syndrome’. The theory proposed to explain this condition is at odds with established facts about thyroid hormone. Diagnostic criteria for ‘Wilson’s syndrome’ are imprecise and could lead to misdiagnosis of many other conditions. The T3 therapy advocated for ‘Wilson’s syndrome’ has never been evaluated objectively in a properly designed scientific study. Furthermore, administration of T3 can produce abnormally high concentrations of T3 in the blood, subjecting patients to new and potentially harmful effects on the heart and bones.’

A lot more scientific evidence has accumulated since 2005 about the definition of normal body temperature, and it is worth highlighting one study from the USA that was published at the end of last year (Obermeyer Z, Samra JK, Mullainathan S. Individual differences in normal body temperature: longitudinal big data analysis of patient records. BMJ. 2017 Dec 13;359:j5468). What is remarkable about this study is the number of subjects included, which were no less than 35,488. The authors excluded children, people with infections and people with severe illnesses. The main finding was that the average temperature of these people was 36.6°C. In fact 95% of the population had a temperature between 35.7°C and 37.3°C. Or put another way, if the cut-off figure of 37°C was to be applied, more than 3/4 of the normal population would have to be classified as hypothyroid.

Interestingly, some of the subjects in this study (2,485, or 7% of the total) had a diagnosis of hypothyroidism (presumably on treatment, though no details were provided) and there was a weak statistical association between hypothyroidism and a lower body temperature. It is possible that this association reflects the well known fact that more than 10% of patients who are on thyroid hormone replacement are inadequately treated and have an elevated serum TSH (Flynn RW, Bonellie SR, Jung RT, MacDonald TM, Morris AD, Leese GP. Serum thyroid-stimulating hormone concentration and morbidity from cardiovascular disease and fractures in patients on long-term thyroxine therapy. J Clin Endocrinol Metab. 2010;95:186-93).

So, most normal people have a body temperature of less then 37 degrees. Although there is an association between body temperature and hypothyroidism, the body temperature test as a diagnostic tool for hypothyroidism performs poorly, in fact less well than flipping a coin.

Adrenal fatigue and adrenal insufficiency

Adrenal fatigue is a name often given to a group of non-specific symptoms that can include tiredness, sleep problems, body aches, digestive problems and nervousness. These are all non-specific problems which are common to other diseases but widely experienced in modern, busy lifestyles.

There is no scientific evidence that this diagnosis exists and doctors are concerned that, if you are told you have this condition, the real cause of your symptoms may not be found and treated correctly. Also, treatment offered for adrenal fatigue is likely to be ineffective and expensive.

Adrenal insufficiency, however, is a real and diagnosable disease. Sometimes known as Addison’s disease or hypoadrenalism, it is a rare, potentially fatal condition which is caused by damage to the adrenal glands or a problem with the pituitary gland. A person with adrenal insufficiency may be dehydrated, confused, or losing weight. They may feel weak, tired, or dizzy and have low blood pressure. Other symptoms include stomach pain, nausea, vomiting, and diarrhoea. Adrenal insufficiency is diagnosed through blood tests and will require life-long, daily treatment with replacement steroid hormones. For further information go to the Addison’s Disease Self-Help Group website (http://www.addisons.org.uk/)

Beware thyroid test services by post

There is a small, but increasing, industry in the UK where private laboratories will measure your thyroid tests through a finger-prick blood sample, or in your saliva or urine. Some even offer genetic tests by post, such as the deiodinase-2 gene (DIO2) variant. These companies will suggest that these tests are better because they are ‘not available on the NHS’. However, these tests are not offered by the NHS because they are unnecessary, a waste of money and the results are frequently meaningless.

One example is reverse-T3 (rT3), which is an inactive degradation product of thyroxine. Firstly,
rT3 is really difficult to accurately measure because it ‘looks’ so similar to thyroxine. With the exception of specialist university laboratories, there is a high chance that what is calculated as your rT3 measurement is actually a highly inaccurate random number. Of course, you will have no way of knowing. Secondly, there is no situation where knowing your rT3 can usefully guide your clinical management. If it was useful, NHS labs would be measuring it.

Taking iodine supplements to support thyroid function

For people with a properly functioning thyroid, iodine is essential as it is required for the production of thyroxine. It is particularly important in women who are pregnant as it is needed to ensure the development of a baby’s brain during pregnancy and early life.

People who are taking levothyroxine, however, do not have a functioning thyroid to absorb iodine and therefore iodine is not required. For patients being treated for hyperthyroidism, taking an iodine supplement is unnecessary and can worsen the condition.

Health food shops are often keen to promote supplements containing iodine or kelp to support normal thyroid function, the production of thyroid hormones, boost your energy levels and even help weight loss. Unfortunately there is no evidence that these supplements can do any of these things. In fact some may even damage your thyroid as they often contain excessive amounts of iodine, even if taken within the dose recommendations on the label.

For further information see the BTF Iodine FAQs. [http://bit.ly/2vLmycX](http://bit.ly/2vLmycX)

See also the article about the low iodine content of milk alternatives, (In the Media, page 12)

Flu jabs, vaccinations and thyroid disorders

We regularly hear from people who have concerns about vaccinations asking whether or not they are safe for people with thyroid disorders. The flu vaccination programme is very well thought through and we are fortunate in the UK to live in a part of the world where vaccinations are freely available.

Having a thyroid disorder does not give you an increased risk of developing flu compared to any other member of the general population. Therefore, unless you fall within one of the following categories who are at greater risk of complications from the flu you are unlikely to need or be offered the flu vaccine:

- people aged 65 and over
- pregnant women
- children and adults with an underlying health condition such as long-term heart or respiratory disease
- children and adults with weakened immune systems

Teenage girls are now routinely offered the HPV vaccine which protects women against developing cervical cancer. There is no reason why a girl who has been diagnosed with a thyroid disorder should not be given this important vaccination. If you have any particular concerns about your vaccinations you should always discuss these with your doctor.

Can dental x-rays harm your thyroid? And can RAI treatment act as a trigger in airport security detectors?

Some patients who have regular dental x-rays raise concerns that the exposure to radiation may damage their thyroid and they should therefore be offered neck guards as protection. One BTF medical adviser assures us that the amount of radiation from a dental x-ray is very small and, therefore, he does not think that occasional mouth x-rays during dental check-ups will harm your thyroid.

If you have recently had radioactive iodine ablation for the treatment of thyroid cancer, you may trigger radiation detectors used for security purposes, for example at airports and seaports. This can occur for up to 95 days after treatment. If you are travelling within this time period you should carry a letter from your hospital to explain your situation.

Are the TSH reference ranges too wide and, if so, should they be narrowed?

There are arguments for and against but what really matters, for most people who are being investigated or treated for thyroid disease, is interpreting the results of the blood tests in the context of the individual and his or her symptoms, so that sensible decisions can be made.

Reference ranges are a guide to defining the limits of normality and helping doctors in making a diagnosis. Any blood test can sometimes be misleading unless its limitations are understood, and tests should not be done unless there is a specific question that it is expected to address.

Reference ranges are derived from testing for a particular chemical such as TSH in the healthy, normal population. To ensure that only the most representative values are included, references ranges do not include the most extreme 5% of values. If the TSH is measured in randomly selected people without any known thyroid disease, there will be a range of values, with roughly two-thirds being around 1-2 milliunits per litre (mU/L).

If we go through the same exercise of working out a TSH reference range, but now apply more strict criteria (for example excluding people with thyroid antibodies or with minor abnormalities in their thyroid ultrasound scan), the reference range is narrower. However, this is complicated by the fact that if we do the same for older people, the upper limit of the reference range goes up. The same is true for some ethnic groups (African Americans) and people with obesity. Conversely, the reference range in pregnancy goes down and the TSH reference range in one geographical area may differ from another because of differences in iodine intake.

Although some might argue that by keeping the range wide some patients with the earliest signs of thyroid damage are being missed, any narrowing of the reference range inevitably means that people with normal thyroid function are at risk of being over-diagnosed and over-treated. Since there is no known clinical benefit from treatment in people with a TSH at the upper end of the conventional reference range, the current consensus is not to narrow this range further.

Is TSH testing sufficient or should doctors routinely test T4 and T3 levels?

In the majority of people, a TSH test alone is sufficient. If the TSH level is not normal, further tests including free T3 (FT3) and/or free T4
(FT4) may be useful and an antibody test may be required. In people recently treated with radioactive iodine for hyperthyroidism, or patients with known or suspected pituitary disease, FT4 should also routinely be checked.

In more than 99% of people with a normal TSH and who have no other reason to have a thyroid or pituitary problem, FT4 and FT3 will also be normal. If all three tests were performed routinely, then around £6m pounds a year would be spent unnecessarily. In someone without thyroid disease, if the TSH is raised then it should be repeated with a FT4 level. If persistently raised, then measuring an anti-TPO Ab tests is useful (but only on one occasion – it is only useful to know whether it is positive or not, the actual level does not contribute much additional information). If the anti-TPO Ab test is positive, it is more likely that the thyroid level may deteriorate over the coming months or years. Thyroglobulin antibodies (TgAB) generally do not add much to anti-TPO Ab results.

If the TSH is low, FT3 and FT4 measurement will diagnose hyperthyroidism. If confirmed, a TSH receptor antibody test looking for Graves’ disease is reasonable. In patients with known or suspect pituitary disease, the TSH level is misleading and FT4 should be measured. This is also true in other situations, such as within three months of treatment of hyperthyroidism (when the TSH may stay lower than it should be) and with some genetic abnormalities of thyroid function. If a patient has a normal TSH but persistent symptoms suggestive of hyperthyroidism or hypothyroidism, the measurement of FT4 and FT3 on one occasion is helpful to rule out a pituitary problem or these other rare conditions.

When monitoring patients already on thyroid hormone, TSH measurement alone is sufficient. If the TSH is not normal, FT4 (and possibly FT3) should also be measured. An exception is patients taking T3 alone, or in mixed preparation, when a FT3 measurement might be helpful. Follow-up measures of antibody tests are not normally required.

My Story

Joshua’s story

Joshua was born on 23 August 2014 by forceps delivery. The doctors queried sepsis and Josh and I stayed in hospital for a further five days on antibiotics. Joshua had heel prick tests done over the five days as they investigated the infection.

Joshua was discharged with no further follow up. He started smiling around ten to twelve weeks old. I noticed from seven to eight months he had poor head control and floppiness but was told boys are slow at developing. We saw a health visitor and Josh was referred to the hospital where he had two magnetic resonance imaging (MRI) scans and a number of blood tests which all came back as normal.

The first MRI after his first birthday showed low myelination and two cysts that were symmetrical on the frontal horns of his brain. The second MRI, twelve months later, showed a small improvement in the myelin yet the cysts were still the same. There were no problems with his hearing or eye sight and he had regular sight tests every four months. So as it stands from September 2015 to present, Josh has a working diagnosis of cerebral palsy. It’s not clearly explained but he’s been put under this umbrella because of his symptoms.

Joshua sees the community care paediatrician, a physiotherapist every six weeks, a speech and language therapist every two to three weeks, and an occupational therapist whenever something is required.

Joshua had an electroencephalogram (EEG) before Christmas 2016 and that came back fine. He has no issues with seizures or epilepsy. Another blood test was requested by a neurology consultant at the children’s hospital due to abnormal thyroid readings. As it turned out these results were abnormal again which brings us to his recent diagnosis of a thyroid issue regarding the TF3 transporter.

Joshua cannot sit up; he can roll from side to side when he wants to but he cannot crawl or walk. His head control isn’t great and at times he can be quite floppy. Joshua has begun babbling and always making noises but there are no words or copying sounds. His physiotherapist and I are working together to improve his poor hand coordination. A splint was fitted in February 2017 for the tight hamstring of his right leg.

Does vitamin D, or its deficiency, have a role in the development of thyroid disease?

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 lifestyles that lead 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. Those with an 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.

With thanks to Prof Simon Pearce, Dr Petros Perros and Dr Salman Razvi for their help with this feature.
Josh has been diagnosed with an extremely rare condition, MCT8 deficiency (also known as Allan-Herndon-Dudley Syndrome or AHDS). He is part of a clinical research trial at Cambridge University and is helping them to establish new facts and reach new conclusions. The medication (known as TRIAC) on the clinical trial seems to be working and leveling out all his bloods so we are hoping and is helping them to establish new facts and reach new conclusions.

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Comment from our medical adviser:

MCT8 deficiency

Thyroid Hormone (TH) is crucial for normal development, especially brain development. TH needs to enter cells to be effective; to do this it is transported into the cell by proteins called TH transporters, located in the cells membranes (outer layer). There are a number of different TH transporters but one of these is particularly important for TH transport into brain cells and is called MCT8. The instructions for making the MCT8 transporter are found on the MCT8 gene, which is located on the X chromosome. MCT8 deficiency (also called the Allan Herndon Dudley Syndrome) is caused by an inability to produce a normal MCT8 transporter and is due to a defective MCT8 gene. With a few exceptions, it only affects males.

Patients with MCT8 deficiency have severe neurological abnormalities, felt to be due to a lack of thyroid hormone during brain development. Most patients cannot sit independently and cannot walk or talk. They also have high levels of a hormone called T3 in their bloodstream. T3 does not require the MCT8 transporter to get into cells of the muscle, so this tissue is exposed to too high a level of TH. This results in skeletal muscle which is metabolically ‘overactive’ and patients often require a high food intake in order to meet the demands of the metabolically overactive muscle, as well as having low body weight and muscle mass.

At present no effective treatment for MCT8 deficiency is available. Effective therapy should at least restore TH signalling in the brain and normalise serum TH levels. Preliminary results indicate that the medication called TRIAC (which is structurally similar to T3) may be effective in MCT8 deficiency. The TRIAC trial in MCT8 patients (https://clinicaltrials.gov/ct2/show/NCT02060474) is designed to determine whether TRIAC is effective in MCT8 deficiency. The primary aim is to evaluate the effect of TRIAC treatment on serum (bloodstream) T3 and other TH levels, with secondary aims being (i) to determine the effect of TRIAC on the toxic effects of the hyperthyroid state in peripheral tissues (such as muscle) and (ii) to observe the effects of TRIAC treatment on the neurological features.

Ailsa’s story

My ambition was always to be successful in my career as a writer and eventually become a successful career woman. The dream was to live in a city as a journalist wearing the pencil skirt with that glossy lifestyle every woman wants. When I was diagnosed with Graves’ disease in 2015, at age 25, all that took a backseat as my health became my priority. The once flamboyant, sociable and outgoing girl became a shadow of her former self. I was underweight, at eight and a half stone and five foot six inches tall, with constant panic attacks, palpitations and muscle deterioration. I was lost. Now, at nearly 28 years old I have battled this disease and come out the other side. This is my story.

The beginning of the disease was more of a shock than anything else. What led me to go to the doctor was arriving home, falling asleep almost immediately and being exhausted. Doctors tried to control the palpitations and panic attacks with beta blockers and carbimazole. The carbimazole was awful as I couldn’t drink alcohol because it gave me palpitations. The party girl ceased to exist, becoming a nervous shell, lying on the couch watching rom coms alone. Friends didn’t understand and constantly told me to just deal with it. The stream of friendships I lost during the illness makes me want to weep but this disease is invincible and cruel.

My confidence and self worth were decreasing by the day. This was a girl who has graduated from a top ten university and once worked as a trainee journalist. After that, I took part time bar jobs that I enjoyed and which helped me to pay my way during my illness. I could only get part time bar work so I decided to go into a full time job that I didn’t enjoy but it paid the bills. Ever since, my dreams have taken a back seat, with survival and anxiety now the key elements of my life. However, I got my strength back after radioiodine treatment and I realised I didn’t want to just survive, I wanted to be free and live my life to my fullest potential. In April 2017, after a year and a half of struggle, depression and anxiety, I felt like me again. I thought, this is now the turning point of my life and I decided to be happy. I left the job I didn’t enjoy and began working at something I thought I would enjoy.

Taking part in the Great North Run (GNR) in September 2017 helped me to conclude my illness by raising £350 for the BTF. The day was fantastic with a feeling of excitement as the Geordie crowds cheered on the runners. Personally, I didn’t find the run as hard as I had imagined it to be and was surprised at my resilience as my legs kept on running. The eleventh mile was gruelling and the last two miles were challenging but I met my target time. I was so happy to not only finish the GNR but to finish my battle with Graves’ disease once and for all with a smile on my face.

I have been on one hell of a journey but I will not let it define me as I still chase my dream of becoming a professional writer. I will never give up on my dream or happiness – they are what every soul deserves. I want my struggle through this illness to be a positive. I want to raise awareness by writing again and doing something I love. I hope I can be a figurehead for other individuals who have suffered with this disease, telling them that it is not the end, you still can follow your path. I will not give up until my goals have been achieved. Like me, you must never forget that you only have one life, so live it how you want to.
INDIGO update

Prof Marian Ludgate (INDIGO Coordinator) writes: We have previously provided news updates on the INDIGO (Investigation of Novel biomarkers and Definition of the role of the microbiome In Graves’ Orbitopathy) project, http://www.indigo-iapp.eu/; an EU* funded research study taking place at the School of Medicine at Cardiff University along with university colleagues in Germany and Italy, plus two small companies who will share their experience and expertise with scientists and clinicians in Cardiff.

The project was summarised recently at a meeting in Italy aimed at increasing public awareness of science (Bergamo Scienza) https://www.bergamoscienza.it/en

As part of the project, some patients with Graves’ disease took their usual thyroid medication plus a probiotic, while a control group took a placebo. The final results are still being analysed but fewer patients taking probiotics reported a worsening of their eye disease compared with those who took placebo.

Probiotics are designed to improve the quality of the micro-organisms in our gut and reduce our likelihood of suffering from a wide variety of diseases, including Graves’ and TED. INDIGO has always benefitted from strong patient involvement and Lynne Kyffin, a member of our ethical review committee, has shared many of her experiences both via the INDIGO website and at various meetings.

She has recently alerted us to a simple precaution that may save you from having heartburn or gut irritation. Please make sure that you are taking thyroid medication in the morning after food. A more detailed account can be found via the ‘new TED videos’ link http://tedct.org.uk/

Here is a summary of her story:

‘At around the same time, I was diagnosed with coeliac, hyperthyroid, later thyroid eye disease and irritable bowel syndrome. I have been taking carbimazole and levothyroxine for five years, during which time my TRAb has reduced from 8.9 to 1.9. When retested later this month I am hoping it should be below normal (1.8). The aim is then to come off all medication.

During this time I have worked very hard to resolve my upset gut through what I eat and drink. I became aware that, having calmed my gut for a few years, I began to experience increasing burning pain, particularly in one area of my gut. My coeliac test results were also showing an increase and I assumed I was inadvertently ingesting gluten. I was retested by biopsy and my gut had no gluten damage. However, it did show signs of ‘irritation’ which the gastroenterologist put down to my prolonged use of carbimazole. I knew that I had lived for several years without irritation from this medication so I checked carefully to see if I was doing anything differently.

Many months previously, I had changed from taking my thyroid medication in the morning (as recommended) to just before I went to bed. I did this so as not to take it at the same time as my calcium tablets (also recommended). Within a week of returning to morning thyroid medication, the burning area in my gut disappeared. I share this in case it helps anyone else suffering due to taking late night medication on an empty stomach!’

*EU (Marie Curie Industry-Academia Pathways and Partnerships (IAPP) action ‘INDIGO’ grant number 612116). ClinicalTrials.gov Identifier: NCT02373995

Fight for Sight/BTF Joint Small Grant Award

A novel pathway regulating adipogenesis in Thyroid Eye Disease: characterisation of spontaneous lipogenesis and validation of novel therapeutic targets

Principal Investigator: Dr Maryse Bailly, Reader in Cell Biology at University College London (UCL) and lead of the ‘Tissue contraction, scarring and mechanoregulation’ research lab at UCL Institute of Ophthalmology. PhD student,

Dr I-Hui Yang, ophthalmologist and oculoplastic surgeon, who came to do a PhD in Dr Bailly’s lab in May 2015, with a prestigious bursary from the Kaohsung Chang Gung Memorial Hospital, Taiwan.

Thyroid Eye Disease (TED) is a severe and potentially blinding disease of the tissues behind the eyeball, commonly affecting patients with thyroid problems. Fat and muscles in the orbit, the bony socket where the eye sits, swell and scar, perturbing eye movements and pushing the eye forward. This gives the patient a staring ‘eye-bulging’ appearance, which creates significant social stigma, and leads to double vision, dry eyes, corneal damage, and potential sight-threatening compression of the optic nerve. TED is poorly understood and treatment options are limited, often leaving patients with permanent disfigurement and double vision. Most of the swelling in TED results from an expansion of the fat behind the eyeball, as local cells, called fibroblasts, turn into fat cells. However, why and how those cells change in TED is still unclear, preventing significant developments in prevention and treatment.

To better understand how fibroblasts turn into fat in TED, our team has grown patient cells in soft gels made of collagen, an essential component of the tissues in the orbit. Under such conditions, fibroblasts from patients spontaneously produce fat, mirroring what happens in TED. Our preliminary study of the cell characteristics and the type of fat they make suggests that fibroblasts in TED do not produce fat as classically found in the main body (such as belly fat), but rather

Continued overleaf
make fat from sugars (a process termed de novo lipogenesis) and/or absorb more fat from the circulation. This project aims to confirm these findings and identify how the cells do this on a molecular level.

TED affects an estimated 400,000 people in the UK. In over 90% of cases, expansion of orbital tissues and fat are responsible for most of the detrimental disease manifestations, and thus an understanding of how this happens is crucial to the development of suitable treatments. Through exploring novel mechanisms driving fat accumulation in orbital cells, this project will identify potential new therapeutic targets that may provide better disease management options for the patients.

New study in radiiodine treatment

Dr Steve Hyer, Consultant Endocrinologist writes: Radioiodine is a well-established treatment for hyperthyroidism and thyroid cancer. Following landmark studies in thyroid cancer (HiLo trial, UK; Estimabl trial, France), there is multicentre evidence that some low risk patients can be safely treated with lower doses of radioactivity than the standard high dose previously used for many decades.

A standard fixed activity of radioiodine is still recommended for patients with benign thyroid disease, aiming to correct the hyperthyroid state as soon as possible. This approach, whilst shown to be effective and safe, results in most patients, sooner or later, becoming hypothyroid and needing replacement long-term levothyroxine treatment. We know that as many as 20-30% of patients on levothyroxine are either biochemically hyperthyroid with the long term risk of osteoporosis or atrial fibrillation, or biochemically hypothyroid with its associated risks of depression and high cholesterol. If the mother is biochemically hypothyroid and pregnant, there is a risk to the development of the unborn child.

Trials to date, aiming to individualise the activity of radioiodine, have had variable results. Clearly if we could identify those patients likely to respond to lower activities of radioiodine and retain normal thyroid function, even if only for a few years, this could be advantageous. Particular patient groups might gain the most from this approach such as women thinking of starting a family in the next few years, teenagers who are notoriously non-compliant with medication and older people living alone already on a lot of medication.

We would like to discuss setting up a trial with a wide group of interested parties including patients with experience of thyroid disease, particularly those who have received radioiodine and those on levothyroxine. We would also welcome endocrinologists, nuclear medicine experts, trial designers and representatives from primary care. If there is sufficient interest, we would like to lead a well-designed multi-centre trial to take a fresh look at how we can best use radioiodine for the treatment of patients with benign thyroid disease.

If you are interested in attending the initial discussion meeting, please contact: Dr Steve Hyer endocrinology-stf@nhs.net or Dr Glenn Flux, Consultant Nuclear Physicist glenn.flux@icr.ac.uk

The British Paediatric Surveillance study of congenital hypothyroidism (CHT)

This study has been looking at the incidence of CHT in the UK (how common it is) and other important issues such as what proportion of cases are temporary as opposed to permanent. The study will also provide information about how paediatricians manage the condition in the UK. The study is supported by the Royal College of Paediatrics and Child Health (RCPCH) and received backing from the BTF.

Information has now been collected for over 600 newborn babies who were screened for CHT using the newborn blood spot (heel prick test) and then followed up for up to three years. Of all the babies who had a positive (abnormal) screening test and needed more tests, 24% did not have CHT, 9% had temporary (transient) CHT, and 67% had permanent CHT and probably need treatment for life.

The study findings also show that the newborn blood spot screening programme is very good at identifying babies with CHT. With screening, just 1 in 100,000 babies are found only because they become unwell. Nowadays around 5 in every 10,000 newborn babies are diagnosed with CHT. This is twice as many as before screening began in 1981 although the reasons for the increase are not known. Information from this study is now helping to improve the screening programme. The researchers are also using the information to look at the different kinds of care that children with CHT receive in the UK.

Contact: rachael.knowles@ucl.ac.uk

Fundraising and Donations

If you are involved in a fundraising event in aid of the BTF please get in touch so that we can send you a poster and other publicity materials. We can also supply BTF t-shirts and running vests, but please allow enough time for us to get the right size for you.

If you are employed, please check with your employer to find out whether it operates a match-funding scheme (matching all or part of what you raise).

Please send us some information about your event and include photographs along with permission to publish them in the BTF News (subject to space) and on the BTF website.

Fundraisers

Paddy Mumby took part in the Royal Parks Half Marathon in London on Sunday 5 October 2017. He says: ’I decided to sign up for the Royal Parks Half Marathon earlier this year, partly to prove to myself I could do it, but also, as my youngest daughter Saoirse was born without a thyroid and partially deaf. It seemed like a great way to raise some money and awareness for the BTF. Having not participated in a marathon, half marathon, or even a 5k fun run before, I wasn’t really sure what to expect. In hindsight my preparation of a couple of two mile runs, downloading several fitness apps and buying a few protein shakes, probably could have been a bit more structured! That said the run itself was very enjoyable. Thirteen miles through four London parks, past Buckingham Palace, up and down Downing Street and around Nelson’s Column, with the sun making an appearance at the end. I finally staggered over the line in 2 hours 26 minutes, which would have been a better time had I not popped into a St John’s Ambulance tent for some paracetamol to get my tired old ankles over the line! Since Saoirse was born (in December 2015) I’ve often felt pretty helpless regarding her condition. From initially not really understanding it to not being able to make
her better, so this was a great way for me to feel I’m helping her in some small way, and hopefully raising awareness at the same time.’ Paddy has raised £590 for the BTF.

Future Fundraisers

Joe O’Callaghan grew a moustache between November 2017 and the end of January 2018. We hope to let you know how Joe got on in the next newsletter along with some before and after photos. For more information please go to: https://www.justgiving.com/fundraising/joe-o-callaghan-moustache

Helena Kontowtł gave up chocolate for the whole of January to raise funds for the BTF. Helena decided to fundraise because she knows first hand the effects of thyroid disorders. Find out how she got on in BTF News 98. For more information please go to: https://www.justgiving.com/fundraising/helena-kontowtł

BTF Trustee Joe Straw is planning to raise awareness about thyroid disease, and how it can affect children, by setting himself an amazing year of challenges. During the course of 2018 he plans to do Joe’s Five@25 and complete a skydive, the Yorkshire Three Peaks (in under six hours), a triathlon, a bungee jump and a half marathon to Mam Tor. To find out more about Joe and his challenges, and to donate to his fundraising page, please go to: https://www.justgiving.com/fundraising/joesfive25

Lucy Sloper will be running a half marathon to Ilchester and back on 26 May 2018. Lucy is supporting the BTF because both she and her daughter Sophia have a thyroid disorder. She has chosen the 26 May to coincide with World Thyroid Day on 25 May 2018. To find out more go to: https://www.justgiving.com/fundraising/lucysloper

Simplyhealth Great North Run (GNR) 9 September 2018 in Newcastle

Our thanks to Luke Hudson who has signed up again this year to compete in the GNR in Newcastle.

Many thanks to Marcia Melton, who will also be running in the GNR.

The BTF has three remaining places for the GNR 2018 so if you would like to compete in this world famous half marathon please email: fundraising@btf-thyroid.org or call 01423 810093.

Virgin Sport British 10K 15 July 2018 London

The BTF has five places for the Virgin Sport British 10K. If you are interested in running for the BTF please email: fundraising@btf-thyroid.org or call 01423 810093.

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.

The BTF would like to thank the following:

Chrisie Herbert on behalf of Eckoh for your kind donation of £514.

Mr and Mrs Lyon for choosing the BTF as their charity to donate £100 in lieu of the free wills service.

Mr Raymond Marsh for his annual donation of £50.

Mrs P Walton who donated over £300 to the BTF in lieu of birthday gifts.

Cura Financial Services who kindly donated £50.

Mr Stanley Lee who has made a number of donations to the BTF.

Mrs Eileen Guppy for her kind donation of £50.

Thank you to Cameron Whitelaw who took part in the Great West Run Exeter Half Marathon in October 2017. Cameron has raised £540 for the BTF.

Thank you to Mrs Sheila Carr, a life long member of the BTF, who sponsored and decorated a Christmas tree at Alverstoke Christmas Tree Festival in aid of the BTF. This is the fourth year that Sheila and her granddaughter Cicely have decorated a tree for the BTF. The tree was decorated with BTF leaflets, key rings, wristbands and drawings.

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In the Media

Low iodine concentration in milk substitutes may mean consumers are at risk of deficiency

In recent years the sales of milk alternatives such as soya, almond and coconut have been growing. This trend is ringing alarm bells, as research has found that most of these products contain very low levels of iodine. Readers who have followed the BTF Iodine Project over the last few years will be aware of the importance of dietary iodine. Particular concerns have arisen because many of the UK’s population have been found to have mild to moderate iodine deficiency.

Researchers at the University of Surrey have measured the iodine concentration of 47 milk substitutes. These include soya, almond, oat, rice, coconut, hazelnut and hemp. Most were found to be naturally low in iodine. In some cases, the products contain around two per cent of the iodine levels found in cows’ milk. While some manufacturers add calcium to match that naturally found in cows’ milk, the vast majority do not add iodine.

Margaret Rayman, Professor of Nutritional Medicine and Dr Sarah Bath, Lecturer in Public Health Nutrition led the research. They are also members of the UK Iodine Group. ‘We are aware that consumers may choose these alternatives for a variety of reasons, including allergy or intolerance to cows’ milk. It is important that they are aware of the low iodine content of milk substitutes and the potential health consequences.’
https://ind.pn/2kiBVQF

Prof Rayman has also made a programme for BBC Radio 4 about iodine. ‘Awesome Iodine’ can be heard as part of a series of programmes about the elements by going to the BBC website. http://bbc.in/2F7oGzD

For further information about the importance of dietary iodine please see the feature on page 6.

Diabetes does not increase thyroid disorder risk

Researchers in Iran have found that adults with diabetes or prediabetes have similar rates of thyroid disorders as healthy adults.

The Tehran Thyroid Study looked at over 3,000 adults to assess the prevalence and predictive factors of thyroid disorders. No significant differences were found among the groups after adjustment for factors such as age, sex, smoking, blood pressure, BMI, thyroid antibodies and cholesterol.

Women exposed to a commonly found environmental toxin have lower levels of thyroxine

Pregnant women who are exposed to higher levels of the chemical perchlorate are more likely to have lower levels of the thyroid hormone thyroxine (FT4). Study data presented at the Society for Endocrinology, British Endocrine Society annual conference in November 2017 suggests that this has the potential to affect foetal brain development.

Perchlorates are chemicals found in water, milk, some foods and other materials such as fertilisers and jet fuel. They are known to reduce absorption of iodine from the blood into the thyroid. This may decrease the amount of T4 produced. T4 is essential for normal foetal brain development. Therefore, any reduction in the amount of T4 passed from a mother to her unborn child could potentially lead to brain development defects in babies.

Prof Bijay Vaidya, Consultant Endocrinologist said in a press release ‘These findings are important because we know that optimum thyroid hormone levels during pregnancy are essential for normal foetal brain development, and this study shows that this common pollutant may be adversely affecting brain development in children.’

Dr Bridget Knight, Senior Research Midwife at Exeter NHIR Clinical Research Facility commented ‘It may be worth adding that this is early work and needs confirming in larger studies. It is difficult for mothers to lower or avoid exposure to this toxin as its fairly widespread, however it is important to make sure that pregnant women have an adequate iodine intake, as the impact of perchlorate exposure appears to be worse in women who are iodine deficient.

If further studies confirm that perchlorate exposure is harmful to health, then public health interventions e.g. defining acceptable levels of perchlorate in water or food items, would be needed.

Comorbidity of autoimmune thyroid disorders and psychiatric disorders during the postpartum period

The time following childbirth (also called postpartum) period is known for the first onset of autoimmune thyroid disorders (AITDs) as well as for the first onset of psychiatric disorders. These two conditions are often misdiagnosed and can be disabling if left untreated. To find out more, Danish researchers looked at a national register of a third of a million women who gave birth to their first child during 1997-2010.

The results of their study revealed that women with first onset AITDs postpartum were more likely to have first-onset psychiatric disorders and vice versa. Researchers are now looking at further studies on the causes of these disorders and why childbirth in particular triggers the onset http://bit.ly/2mgBY4X

Scottish Parliament debate on treatment of thyroid patients

On 22 November the Scottish Parliament held a debate on the motion ‘Thyroid Patients Deserve Fair Treatment.’ You can watch a video of the debate on this YouTube link. https://www.youtube.com/watch?v=zIACR_lvNI&sns=em
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. Medical queries should be addressed 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 their advice is provided for information only. For specific medical advice 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.

Caffeine and levothyroxine

JB asks: I have taken levothyroxine for many years. Today, when I collected my medication, the pharmacist asked me when I had taken it last and I said not today. He said that I should take it immediately after having taken the tablets as caffeine had a detrimental effect on the levothyroxine. I have never heard this before and would be interested in your comments. If this suggestion were correct, would decaffeinated tea be okay for my early morning tea?

Our medical adviser replies: Levothyroxine is best taken first thing in the morning. It is best taken with water as caffeine does affect the absorption of levothyroxine, but as you have been taking it this way for years without ill effects it would be best not to change your routine. However, if you would prefer to leave a little gap before taking your tea or change to decaffeinated tea it should not do you any harm. Some people take their tablets at night because it works best for them but, consistency is more important.

British Thyroid Association guidelines on benign nodules

AMG asks: I had a fine needle aspiration (FNA) biopsy on a thyroid nodule in the summer. This came back with an abnormal result that was downgraded to benign. In October, I had another FNA biopsy on the same nodule and that came back as non-diagnostic and so, had another FNA biopsy on the same nodule a week ago that also came back as benign. In the same letter I was asked to come in again in a further two weeks time for yet another FNA biopsy on the same nodule ‘for completeness’. The reason given to me was the British Thyroid Association (BTA) guidelines suggest that a non-diagnosable biopsy result, followed by a benign one, requires a further FNA to register as benign, before the case can be closed. I would like to know if this is a BTA guideline or best practice?

Would this be the best way forward because my neck/the nodule still hasn’t recovered from the last biopsy?

Our medical adviser replies: Biopsy results are usually interpreted in the context of an ultrasound grading of the nodule. It is difficult to comment on this case without knowledge of that. If there were concerning features on an ultrasound scan, then I can see why an additional biopsy might be required, particularly if an initial biopsy was not in keeping with the ultrasound grading, for example, a benign biopsy in the face of a nodule that looks like a cancer. I’m not aware of any guidance that another biopsy is required after a technically inadequate biopsy and then a benign biopsy.

Iodised salt

MO asks: I am in my early fifties and in the menopause. I have a slightly enlarged thyroid, of which I have had biopsies that showed there was no malignancy. My thyroid is also functioning normally.

I do not eat dairy products but feel I may be deficient in iodine.

Would you recommend iodised cooking salt or any other products containing iodine, such as ‘Menopace’ (a food supplement for women during and after the menopause)?

Our medical adviser replies: Iodised table salt is difficult to get hold of but not impossible. However, it would not provide you with enough iodine for your needs. ‘Menopace’ does contain some iodine and this may well suit you, but this depends on your diet and it is important that you do not take too much.

Here are some links about diets and iodine, which you may find useful. However, as with any medical condition, you should discuss with your GP any change in your diet or if you are considering taking any supplements.

http://www.btf-thyroid.org/information/239-iodine-fact-sheet
http://www.btf-thyroid.org/information/108-thyroid-and-diet-factsheet

Contraceptive pill and thyroid

HC asks: On your website you state that the contraceptive pill can affect thyroid hormones. Do you have any more information on how thyroid hormones are affected?

Our medical adviser replies: Contraceptive pills containing oestrogen may have an effect on blood results. This will influence the dose of levothyroxine a person requires, sometimes by up to 30%. Anyone considering taking the contraceptive pill should discuss this with their GP.

Flu vaccine and radioactive iodine treatment

SO asks: Would you be able to clarify if someone who has had radioactive iodine therapy two weeks ago is able to receive their flu vaccine?

Our medical adviser replies: Yes, it should be no problem to have the flu vaccine, providing you have had it before without any adverse effects. If you have not previously received it, it may be advisable to wait at least four weeks after your radioactive iodine treatment.

Hyperthyroidism and radiofrequency ablation

WM asks: I have been diagnosed with a borderline hyperthyroidism with a right side hot nodule. I am on a daily dosage of 5mg of carbimazole, which I have been taking at various dosages over a period of three years.

My consultant recommended two other alternative methods of treatment that are available on the NHS, namely radioactive iodine treatment or surgery. However I am hesitant in considering either of these...
options as I do not feel at this stage I need this course of treatment. I am sixty eight years old.

A third alternative suggested to me was ultra sound percutaneous radiofrequency ablation (RFA) for benign thyroid nodules. However I am informed that this procedure is not available locally.

Could you kindly put me on the right track if the treatment is available locally or in London, so that I am able to study this method of treatment or any other new procedure that may be suitable?

Our medical adviser replies: I understand that the procedure may be available at University College Hospital, London.

National Institute for Clinical Excellence (NICE) guidance, published in 2016, indicated that approximately 50% of patients with a ‘hot’ nodule, continued to need carbimazole after the procedure.

In the systematic review of 284 patients, 60 patients with ‘hot’ nodules were given methimazole at doses sufficient to maintain TSH within the normal range before RFA treatment. After RFA treatment, 29 patients continued to need some dose of this medication to maintain euthyroidism based on TSH measurements and symptoms.

Hashimoto’s hypothyroidism and giant cell arteritis

RW asks: I have had Hashimoto’s hypothyroidism since 1994. Last week I was diagnosed as having giant cell arteritis (GCA). Please could you let me know if there is a connection between these two conditions?

Our medical adviser replies: Giant cell arteritis is another ‘auto-inflammatory’ disease. There may be a weak association between the two conditions developing in the same person, but it is fairly weak. It is unlikely that the Hashimoto’s will interfere with the GCA treatment or vice-versa.

Age-related reference range for TSH/thyroid hormone levels

HE asks: My son has had a thyroid function test and I am trying to find out the range for his age group. I think my GP is using the scale for older children. He is two years and five months.

Our medical adviser replies: You are quite right; there are age-related differences in the reference range for TSH/thyroid hormone levels. However, the difference between the reference range for a two year old as opposed to a twelve year old is relatively small. It is worth remembering that a small proportion of the healthy population will have values outside this range because ‘normal ranges’ only encompass around 95% of the healthy population.

Perhaps of greater importance is knowing which biochemical blood tests are used locally – the reference range can vary quite a bit when one particular blood test is compared to another. I think the way forwards would be to speak to your family doctor – raise these issues with him or her – and see what they have to say. They may need to link in with the local biochemistry department to provide you with an answer.

Hemithyroidectomy waiting list

CT asks: I was diagnosed in September 2017 with a thyroid nodule T3 and I was advised to have a hemithyroidectomy. I have been put on an over forty week waiting list. I am worried that this is too long and would like to know if this wait is normal and what I should do? I have spoken to my GP and he said that an alternative hospital would mean the same wait.

Our medical adviser replies: I suspect that you have a thyroid nodule and have been investigated with an ultrasound and a fine needle aspiration biopsy (FNA) of the nodule. From your letter, it seems that the results of the FNA was categorised as a Thy3 nodule. In such a situation, doctors usually recommend removing the nodule and the surrounding thyroid lobe (called a hemithyroidectomy) in order to determine whether there is any evidence of cancer within the nodule (this is called diagnostic surgery because we are performing surgery in order to achieve a diagnosis). Statistically speaking, the chance of there being a cancer within the nodule is approximately 5-30% (depending on the exact report of the biopsy). At present, there is no other way to definitively exclude a cancer within a Thy3 nodule.

In England, under the NHS constitution, patients should wait no longer than 18 weeks from GP referral to treatment, and if this is not achieved, the NHS is obliged to take all reasonable steps to offer a range of suitable alternative providers. I feel that forty weeks is too long to wait for this operation. I would suggest that you discuss this issue again with your GP and see if you can be referred to another hospital to have the surgery performed sooner. If that is not possible, I would suggest you write to your local MP.

Thyroid Eye Disease and smoking

M comments: I was diagnosed in March 2016 with Graves’ disease after losing nine kilos in a short period of time. I was also a smoker. In June 2016, I was also diagnosed with thyroid eye disease, with symptoms of bulging sore eyes and double vision. I was advised by doctor to stop smoking immediately, so I did.

My thyroid is back to normal now, but I was told to continue my medication for a while after receiving orbit decompression surgery, due to eye disfigurement. I am now recovering. It has been an incredibly long lonely road. I have not smoked since my diagnosis and I will never ever smoke again, ever.

Flame Retardants and Thyroid Cancer

JH comments: I was interested to read your article on ‘Flame Retardants and Thyroid Cancer’ (BTF News 95). I am a patient with an interest in polybrominated diphenyl ethers (PBDEs).

PBDEs are oestrogenic and are thought to cause breast cancer. There is a correlation between the introduction of PBDEs in the 1970s and the increase in breast cancer but no proof. PBDEs are structurally similar to thyroid hormone and in effect ‘thyroid hormone mimics’, they behave rather like thyroid hormone. Hence, they have many disrupting effects on thyroid hormone action at various levels. PBDEs are associated with lower fT4 levels, they bind to serum transport proteins especially TTR, disrupt the binding of T3 to receptors and impair T4 to T3 conversion. High maternal PBDE levels are linked to lower IQs in infants. For these reasons in 2004 the production of the Penta and Hexa (5 and 6) forms was banned in the EU. Unfortunately, PBDEs are highly persistent with very long elimination half-lives and the human burden is likely to continue for decades. The use of TetraBDEs was phased out in recent years.

The increased risk of papillary thyroid cancer is associated with TetraBDEs which are used in items such as televisions. Getting rid of your sofa will not reduce your chances of thyroid cancer! However, if you have old furniture, manufactured before 2004 I would consider replacing it, especially if the foam is exposed or beginning to crumble. The same applies to the old foam backed carpets.

This is a fascinating subject. I hope BTF News will be able to publish more articles on EDCs (endocrine disrupting chemicals) and in particular PBDEs as it subject that is overlooked.
Bristol

The group meets on the second Wednesday of each month. New members are requested to contact Michelle in advance to book onto a session.

**Location:** The Old Library, Muller Road, Eastville BS5 6XP.
**Contact:** Michelle on 07759 150727 or email michelle.griffiths@live.uwe.ac.uk

Michelle says, ‘The Bristol group had a really promising end to 2017. In its first few months, the group has supported 27 people with a range of thyroid diseases, and their supporters. The monthly group format has mainly been a meet-up and discussion group, with a well-received mindfulness session run by ‘Oasis Talk’, a local Improving Access to Psychological Therapies (IAPT) service.’

‘The group will continue to run every second Wednesday of the month. We do know, however, that not everyone can make the evening sessions so we hope to organise a quarterly patient information event with visiting speakers which will take place on Saturdays in 2018.’

‘In addition to running the group, this year, I have offered telephone support to many people, locally and nationally. I have also delivered a programme of teaching and training across the Bristol area to raise awareness of the psychosocial impact of thyroid disease and the support needs of patients. This has involved sessions at the University of the West of England, the Bristol Eye Hospital, and at the Bristol Royal Infirmary. I have also spoken at the TEDct Bristol patient information event. In addition, I have conducted a systematic review of the literature to look at the effectiveness of psychological and social interventions in supporting people with thyroid disease to cope. I hope this work will help towards developing evidence-based support for people living with thyroid disease in the future.’

**Cambridge**

**Next meeting:** Saturday 12 May 2018 10am-12.30pm.
**Contact:** Mary on 01223 290263 or email butterflyecho@hotmail.com
**Location:** Weston Colville Reading Room, Chapel Road, Weston Colville, Cambridge CB21 5NX.
**Programme:** The guest speaker will be Dr Nikkie Umaru and her presentation will start at 11am.

Do you have questions relating to medicine usage and healthcare in general, that you have always wanted to ask but never got the opportunity or felt comfortable to ask? Would you like to share your experience and ideas and learn from others in a familiar environment?

The ‘Community Conversations about Medicines Initiative’ facilitates engagement in an informal way to support people in getting the most benefit from their healthcare services.

Dr Nikkie Umaru, a practising pharmacist registered with the General Pharmaceutical Council UK, will discuss all matters related to medicines use, medication safety, self-care, pharmacy and healthcare related matters with the group.

This outreach initiative is supported by The Eastern Academic Health Science Network.

**Edinburgh**

**Next meeting:** The Edinburgh BTF support group meets on the last Tuesday of each month except for school holidays.
**Location:** Liberton High School, Gilmerton Road, Edinburgh EH17 7PT.
**Contact:** Margaret Tel: 0131 664 7223 or email: M2mccgregor@aol.com

**Leeds (Wharfedale)**

**Next meeting:** TBA. Check the BTF website for further details.
**Contact:** Caroline on 0113 288 6393 or email: leefields237@btinternet.com

**Milton Keynes**

**Next Meeting:** Saturday 3 March 2018 10.30am to 1pm.
**Location:** The Pavilion, Open University, Milton Keynes MK7 6AA.

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.

A voluntary donation of £2.00 is requested to cover the cost of room hire.

Contact: Wilma on 01908 330290 or see www.thyroidmk.co.uk or find us on Facebook.

Follow us on Twitter @ThyroidMK

Future Meetings: Saturday 7 July 2018 and Saturday 6 October 2018.

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**Facebook groups for online support**

Would you like to get in touch with others? Our facebook groups are a safe and friendly space to share experiences and support each other. Current groups are for Hyperthyroidism, Thyroid Eye Disease, Thyroid Cancer and Parents of Children with Thyroid Disorders. Find the groups online or email info@btf-thyroid.org and let us know you’d like to join.
BTF LOCAL COORDINATORS

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

<table>
<thead>
<tr>
<th>City</th>
<th>Coordinators</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bristol</td>
<td>Michelle (U)</td>
<td><a href="mailto:michelle.griffiths@live.uwe.ac.uk">michelle.griffiths@live.uwe.ac.uk</a> (for local group information only) 01223 290263</td>
</tr>
<tr>
<td>Cambridge</td>
<td>Mary (O,R,U)</td>
<td><a href="mailto:butterflyecho@hotmail.com">butterflyecho@hotmail.com</a></td>
</tr>
<tr>
<td>Milton Keynes</td>
<td>Wilma (U)</td>
<td>01908 330290</td>
</tr>
<tr>
<td>Edinburgh</td>
<td>Margaret (PC)</td>
<td>0131 6647223</td>
</tr>
<tr>
<td>Leeds</td>
<td>(Wharfedale) Caroline (O,U)</td>
<td>0113 2886393</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>City</th>
<th>Coordinators</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dave</td>
<td>(PC,CS,RAI)</td>
<td>07939 236313</td>
</tr>
<tr>
<td>Jackie</td>
<td>(PC,CS)</td>
<td>01344 621836</td>
</tr>
<tr>
<td>Gay</td>
<td>(G,TS)</td>
<td>020 8735 9966</td>
</tr>
<tr>
<td>Angela</td>
<td>(U)</td>
<td>01943 873427</td>
</tr>
<tr>
<td>Karen</td>
<td>(U)</td>
<td>01628 529212</td>
</tr>
<tr>
<td>Maria</td>
<td>(U)</td>
<td>020 87934360</td>
</tr>
<tr>
<td>Jane</td>
<td>(GR,RI,TED,G,U)</td>
<td>01737 352536</td>
</tr>
<tr>
<td>Peter</td>
<td>(TED,GR)</td>
<td>01200 429145</td>
</tr>
<tr>
<td>Penny</td>
<td>(Ch)</td>
<td>01225 421348</td>
</tr>
<tr>
<td>Kellie</td>
<td>(C)</td>
<td>07725 726860</td>
</tr>
</tbody>
</table>

KEY

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

PLEASE NOTE: BOTH LOCAL AND TELEPHONE COORDINATORS ARE VOLUNTEERS AND ALTHOUGH THEY WILL MAKE EVERY EFFORT TO BE AVAILABLE AT THE TIMES PUBLISHED THIS CANNOT ALWAYS BE GUARANTEED.

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
- **Irish Cancer Society**  www.cancer.ie  email info@thyroidcancersupport.ie
- **Butterfly Thyroid Cancer Trust** Tel: 01207 545469  www.butterfly.org.uk
- **Cancer52**  www.cancer52.org.uk
- **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

<table>
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<tr>
<th>Members living in the UK</th>
<th>By cheque</th>
<th>By standing order</th>
<th>Lifetime membership</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Full: £25 per year Concession: £15 per year</td>
<td>Full: £25 per year Concession: £15 per year</td>
<td>£200 by cheque</td>
</tr>
</tbody>
</table>

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

The Virgin Sport British 10k Run in Westminster, London is taking place on 15 July 2018. Run by Trafalgar Square, the Embankment, Big Ben and more. It’s also a huge street party, with music at every kilometre.

We have some places left for the run - email fundraising@btf-thyroid.org for an application form.

The Simplyhealth Great North Run in Newcastle-upon-Tyne is taking place on 9 September 2018. It attracts nearly 60,000 runners of all abilities – from world-class runners to first timers. It’s the world’s largest half marathon and has a fantastic atmosphere.

We have some places left in this sell out run - email fundraising@btf-thyroid.org for an application form.