The BTF awards £40,000 into research projects

Funding and supporting research projects into thyroid disease is central to our work at the BTF. Thanks to the support of our members, since 1997 we have awarded over £400,000 into thyroid research projects.

We are delighted to have granted two BTF Research Awards of £20,000 each in 2019. The two projects will focus on congenital hypothyroidism and thyroid cancer, two thyroid disorders which have seen an increase in diagnoses in recent years.

Firstly, a congenital hypothyroidism project will seek to understand the underlying causes of the increasing numbers of babies being diagnosed with mild or transient congenital hypothyroidism. Awarded to consultant endocrinologist Dr Nadia Schoenmakers (pictured above), it will investigate the potential link between deficiencies of minerals (iodine, selenium and iron) in the diet (crucial for the development of thyroid hormones and essential for the development of the nervous system and brain) and/or excesses in environmental pollutants (perchlorate, thiocyanate and nitrate) and congenital hypothyroidism.

The study will look at more practical techniques to measure minerals and chemicals in the body. It will then compare levels of substances in children with congenital hypothyroidism against those with normal thyroid function to see whether any differences can be detected.

The second award was presented to Dr Hannah Nieto (below). Her thyroid cancer project will investigate the possibility of differentiating benign from malignant thyroid lesions using nanopore sequencers. This technology has the potential to sequence genetic material from fine needle aspirate testing faster. This could enable patients to be diagnosed in a single day and avoid unnecessary surgery for some and allow more targeted individualised treatment for those needing it.

Both of these projects fulfil our mission to better understand thyroid disease and improve treatment for people living with thyroid disorders. More details about these research projects, and previous ones, can be found here https://bit.ly/2DRDddI

Dr Schoenmakers told us: This is a project that we have been so keen to undertake for a long time now, and it is really fantastic to know that we now have the means to set this up.

New look BTF

You may have noticed we’ve changed our colours and our logo! Whilst we look different, our pledge to our members remains the same: to provide information and support to patients and their families living with thyroid disorders.

An important part of this work is to ensure this information is easily accessible. As well as talking to our existing members who know us as ‘the BTF’, we want to ensure those who are newly diagnosed with thyroid disease can find us easily. That’s why our new logo has been designed to incorporate both the BTF initials and the words ‘British Thyroid Foundation’. We’ve also opted for fresh, clean layouts in all our communication materials. This is designed to help you access information as quickly as possible.

Our new look website will be launched shortly. Here you will find easy to navigate menus and the information you need at the click of a mouse.
Welcome to...
Our newsletter editor and communications officer Anna Woolven. Anna has been behind some of the changes to this edition and is always interested in hearing feedback and suggestions for future newsletters. Please get in touch with Anna editor@btf-thyroid.org.

Farewell to...
Previous Chair of Trustees Richard Bliss and Trustee Mark Lansdown, both of whom have generously given their expertise and guidance over several years. We would like to thank them both for their commitment to the BTF.

Janis Hickey receives MBE
BTF founder Janis Hickey recently received her MBE from HRH Prince Charles at the investiture at Buckingham Palace. Janis said: It was a proud moment to walk into the ballroom to receive the award and discuss the BTF with HRH Prince Charles, who was interested in the work we do. I would like to say a big ‘thank you’ for the many lovely messages of congratulation I received from members.

Janis is pictured (second from right) with her family after the ceremony.

You said ◄ we did
Thank you to all our members who took part in our recent survey. Your feedback helps us to continue to shape our services to your needs. Below is a summary of the results:
► We particularly value your literature, newsletter, medical query service and telephone helpline.
► We continue to develop our resources for patients. Our medical query service is offering more support than ever (nearly 50 hours per month) and we have recently expanded our telephone contact network. We work alongside medical professionals to develop straightforward, factual literature to support you.
► It is sometimes difficult to find information on your website.
► We will shortly relaunch the BTF website. This includes easy to navigate menus, more patient stories and interactive content, including videos.
► Providing information to GPs, and helping to fund research, is really important to us.
► This year we have invested £40,000 into thyroid research. We also continue to offer our literature service to hospitals and GPs. Over the past year alone, we have sent out over 22,000 leaflets for them to give to patients.
► We love reading about patient stories and members’ letters.
► We have introduced a new ‘Coping with’ feature and increased the number of patients’ stories and letters.

Joe Straw’s survey
Thank you to everyone who contributed to BTF trustee, Joe Straw’s, survey into how physical activity levels affect quality of life when living with hypothyroidism. The dissertation results show that those with hypothyroidism who reach or surpass the physical activity guidelines, regardless of type of activity, have a higher quality of life than those who do not. Joe will be continuing his studies from September undertaking a Masters in Physical Activity & Health.

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Office enquiry line open: Mon to Thurs 9.30am-4pm. In the event of a complaint, please address your correspondence to ‘The Chair of Trustees’.

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Next issue of BTF News: October 2019

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

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

If you have any comments or queries regarding this publication or on any matter concerning the BTF we would be pleased to hear from you.
Projects and research update

The BTF is focused on several thyroid-related areas with the aim of raising awareness, assisting with research and improving the patient experience.

Thyroid Eye Disease

The BTF works with representatives of professional organisations and the Thyroid Eye Disease Charitable Trust (TEDc) on the Thyroid Eye Disease (TED) project.

Dr. Rachna Murthy, who heads Cambridge’s regional tertiary referral service for thyroid eye disease, reports on developments in the UK which are helping to guide TED treatment and monitoring:

2019 to 2020 has proved to be an exciting time for the Cambridge TED research team. In September the annual Cambridge Ophthalmological Symposium was organised to focus solely on thyroid eye disease. Professors Tim Sullivan and Marian Ludgate chaired the meeting. I was invited to speak about my research on biomarkers and how they are affected by smoking and radioactive iodine, which can prolong and worsen the disease. Endocrine drives, in this instance, are radio-iodine treatment of Graves’ disease which can lead to hypothyroidism, and endocrine instability – prolonged hypo- and hyperthyroidism.

Careful monitoring has helped the team of experts at Addenbrooke’s Hospital in Cambridge to reduce the rate of surgical decompressions in the city significantly compared with the published national average. I was delighted to speak on ‘What Really Works’ at the 5th biennial International Thyroid Eye Disease meeting in Singapore. My fellow, Dr Jonathan Roos, won the conference’s best presentation prize. This was for his talk describing a new MRI-based imaging approach for TED pioneered in Cambridge. It is hoped this will help to better understand and measure the disease, thereby guiding treatment.

More information about TEAMeD’s work can be found on the BTF website here https://bit.ly/2XeIP0b

Hyperthyroidism. Survival in patients with Graves’ disease: Does treatment matter?

Dr Onyebuchi Okosieme writes: Thyroid gland overactivity or hyperthyroidism affects about 640,000 people in the UK. Most cases are due to Graves’ disease, a condition in which the body produces antibodies that stimulate the thyroid gland to become overactive. Three treatments are available for Graves’ disease namely antithyroid drugs, radioactive iodine, and surgery, but the approach to treatment varies from place to place.

In this study we looked at records of 4189 patients treated for Graves’ disease in South Wales to see whether the type of treatment affected long-term risks of death and cardiovascular disease. We divided patients into three groups according to whether they were initially treated with antithyroid drugs or whether they received radioactive iodine with successful or unsuccessful control of hyperthyroidism.

We found that patients successfully treated with radioiodine had reduced risk of death or cardiovascular events compared to those treated with antithyroid drugs, a benefit that was not seen with unsuccessful radioiodine treatment. In addition, patients who remained overactive after one year of diagnosis had higher risk of death and cardiovascular disease irrespective of the type of treatment received.

Our findings show that regardless of the method of treatment, early and effective control of hyperthyroidism improves survival in patients with Graves’ disease.

BTF patient information event for hyperthyroidism and thyroid eye disease

We will be hosting a free information event on Saturday 5 October 2019 at the Crowne Plaza Hotel, Wellington Street, Leeds LS1 4DL, from 10.30am to 4.00pm.

The aim of the meeting is to provide information about all aspects of hyperthyroidism and thyroid eye disease. We have lined up some excellent professional speakers who will talk about a range of subjects including; what is the thyroid and what can go wrong, thyroid surgery, radioactive iodine treatment, and the diagnosis and management of thyroid eye disease. There will also be plenty of opportunity to ask questions, to meet other people and to share and discuss common experiences.

Pregnancy

As reported in BTF News 99, we are pleased to announce that the pregnancy and thyroid protocol developed in 2018 by Dr Anh Tran, a Surrey-based GP, has been approved by EMIS, an electronic patient record system commonly used by GPs. EMIS now include the protocol in their library which will hopefully enable GPs to improve their management and monitoring of women with hypothyroidism who are pregnant or trying to conceive. The protocol needs to be manually activated and further information about how to find it will be available on the BTF website.

Dr Tran presented the findings of her study to delegates at the BTA Conference in May 2019.

Projects and Research update is continued on page 12...
Fundraisers and Donations

Thank you to everyone who has raised funds for the BTF

Your donations make a difference to the thousands of people living with thyroid disorders across the UK. If you are involved in a fundraising event in aid of the BTF please get in touch so we can send you a fundraising pack and help you advertise your event. We also supply BTF t-shirts and running vests but please allow enough time for us to post them to you.

Please send us some information about your event and include a photograph along with your permission to publish your details in the BTF News (subject to space) and on the BTF website. If you are employed, please check with your employer to find out whether it operates a match funding scheme.

In memory of Lorna Bruce

The family of Lorna Bruce, a thyroid cancer patient, kindly donated her funeral collection and has pledged to continue to donate money to the BTF’s work. Her daughter, Louise, explains: Mum’s final thyroid cancer was very rare and it was not easy to get any information on it. We accessed a lot of information from the BTF website, which was very useful. We feel it is so important to have as much information available on the rarer cancers.

I have a few family members, including my husband, who are affected by thyroid conditions and thyroid cancer. Living in a remote and rural location it is even more important to be able to access information online and talk to someone over the phone.

Lorna’s family donated £480 to the BTF.

Braving Sheffield’s hills for the BTF

Following his Five@25 challenge last year, BTF trustee Joe Straw and his dad Ian, took part in the Sheffield Half Marathon in April 2019. Joe explains his reasons for supporting the BTF: I was born with congenital hypothyroidism and two years ago began volunteering with the BTF. I have seen firsthand the fantastic support they provide to people living with thyroid disease, from babies to older people. Joe and Ian’s efforts raised £247 for the BTF.

Keep on running

Terri Ballard-Vass took part in the Thorpe & Egham Half Marathon and also in the Brighton 10k for the BTF. Terri was keen to raise the profile of hypothyroidism, which she was diagnosed with in 2009. Terri says: I believe this illness is very under publicised, especially as it affects every part of our lives. Terri raised £200 for the BTF.
Raising funds and awareness
Since its introduction 40 years ago, the heel prick test has been vital in diagnosing a number of health conditions, including congenital hypothyroidism. To raise awareness about the importance of this screening, which helped identify her stepdaughter’s condition, Vivian and her colleagues recently held a bake off. Named ‘The Great CAT’ish Bake Off’, the challenge encouraged some friendly rivalry among the Control Accounts Team and raised £313.26 for the BTF’s work.

Netting a big plus for the BTF
A big thank you to Capita Plusnet Team for their fundraising efforts, inspired by Operations Manager, Sue Kisby, who was diagnosed, and successfully treated for, thyroid cancer in February 2018. To celebrate Sue’s first year of being cancer free, Cheryl McMullan from the BTF and Mark Lansdown, consultant endocrine surgeon and past BTF trustee, went along to receive the cheque for £1,000.

Graduating with flying colours in Cambridge half marathon
Bishop’s Stortford Running Club members, Peijie Zhu and Serena Beresford, took in the sights of Cambridge University colleges during the Cambridge half marathon in March. The historical landmarks, supportive crowd and flat course all helped the two runners on through the 13.1 mile course and both highly recommend the race to runners of all levels.
Serena and Peijie raised £180 for the BTF.

Marathon effort for Natasha
Congratulations to Natasha Hull who completed the 2019 London Marathon. Natasha explains her motivation for undertaking the challenge: Whilst I was in the midst of my illness it was the most that I could do to get off the sofa and make a cup of tea. It would literally feel that I had run a marathon, I felt that exhausted. So 18 months after my total thyroidectomy (the removal of my whole thyroid) that is exactly what I did!
Natasha raised £1,190 for the BTF.
My story

Billy Wright

The MasterChef finalist was diagnosed with thyroid cancer in 2016. He explains why he is keen to get men talking about their health

When I noticed a lump in my neck, I ignored it for more than 12 months. I had suffered from swollen glands and sore throats as a child and thought the swelling was down to this.

At the time my symptoms appeared I was really busy. I had been cast into the spotlight after competing in MasterChef and was setting up my business with fellow finalist Jack Layer. I think my reluctance to seek medical help was probably due to a typical ‘British stiff upper lip’ approach to my health. I think this attitude is quite common in men.

A year after the lump first appeared, I then developed a persistent cough. It was only then that I went for a checkup. Doctors originally thought I may have pneumonia but an ultrasound scan revealed I had two cancerous tumours in his neck.

I received my diagnosis of thyroid cancer with a mixture of emotions. Firstly, it was one of relief as I had been through five weeks of testing for Lymphoma, which is much harder to treat. Next came the realisation I had to deal with a cancer I knew absolutely nothing about.

I then had my thyroid removed during a lengthy operation at New Victoria Hospital in Kingston. This was followed up by radioactive iodine therapy (RAI ablation) at the Royal Marsden Hospital in Surrey. Due to the radioactivity this treatment takes place in an isolated room to prevent the radioactivity adversely affecting others with a healthy thyroid. I found this period of physical isolation one of the most challenging aspects of his treatment. The room had a stable door, so people could visit for a short amount of time, but I wasn’t able to really go near anyone for days. It was pretty intense.

During this time I found my family and business partner, Jack, a great source of support. My mum had previously undergone treatment for bowel cancer and I was able to talk to her about my concerns and treatment. My dad and brother were very cool throughout too. Some friends did find it difficult to know how to react to the diagnosis. They didn’t really know how to take it.

During the thyroidectomy (thyroid removal), a nerve near my voice box was damaged. This resulted in my voice becoming low and squeaky for about a month afterwards. After a few sessions of voice therapy, my voice thankfully returned to normal.

I have been taking levothyroxine, a synthetic version of thyroxine, ever since. I have experienced some feelings of gogginess and lethargy but regular tweaks to my medication have largely kept these symptoms at bay.

My experience of thyroid cancer has encouraged me to share my story with others in a similar position. My message to others is to stay positive and get active as soon as you can. I just thought to myself ‘the operation has gone well and I need to try and return to normality as soon as my body would allow me to.’

My only regret is that I did not get my lump checked earlier. I would urge people to check their neck regularly and seek medical advice if you discover any unusual lumps.

Support and information on thyroid cancer are available on the BTF website https://bit.ly/1scgvel. Many patients also find our network of volunteer telephone contacts and local support groups a valuable resource. Please refer to the back page of BTF News for further details.
My story

Comment from our medical advisor, Dr Salman Razvi:

Treatment for thyroid cancer depends on the type of cancer and the stage at the time of diagnosis. It will typically occur within 30 days of diagnosis.

In most cases of thyroid cancer a total thyroidectomy will be performed. Sometimes only one side will be removed (hemithyroidectomy or lobectomy). Some lymph nodes may also be removed.

The hoarseness Billy refers to can be a common side effect of surgery, but is usually a temporary side effect.

If you have been diagnosed with papillary or follicular thyroid cancer you may have RAI ablation within a few weeks of surgery, depending on the size of the tumour, type of cancer and risk of residual diseased thyroid cells. The thyroid gland is the main organ in the body that takes up iodine.

The purpose of RAI ablation is therefore to take up radioactive iodine into the remaining thyroid cells, whether normal or cancerous, and destroy them.

A low-iodine diet is often recommended prior to our RAI treatment. This is to encourage better absorption of the radioactive iodine by any thyroid cells. The treatment is usually given in the form of a capsule at hospital. During this time, you will be isolated from other people to prevent their exposure to radioactivity.

RAI ablation will not be given if patients are currently taking (or have taken in the past 12 months) anti-arrhythmic medication, such as amiodarone, due to its high iodine content. Nor will it be given to pregnant or breastfeeding women.

Further information about what to expect during treatment for thyroid cancer is available from the BTF ‘Thyroid Cancer. For Patients. By Patients’ booklet. This can be downloaded from the BTF website https://bit.ly/2tqjB1I or by contacting us for a hard copy info@btf-thyroid.org.

Saira Batlay

In her moving blog, Saira writes about finally seeking help for her symptoms of hypothyroidism

A cloud followed me everywhere. Its shadow enveloped me in its murky darkness; numbing out my senses, fogging my brain, ultimately drenching my life with woe and misery. Or so it seemed. For it was not my environment or my relationships which were responsible for the strain. It was my physical predicament. Over a period of a few months, I aged multiple years. It was hard to breathe while lying down, I had to prop myself up on pillows to allow for a smooth flow of oxygen to my lungs.

After furiously searching for the root of my ailment on the internet, I self-diagnosed it as ‘sleep apnea’. The cramps at night were written off to lack of calcium and ‘restless legs syndrome’. The growing lump at the base of my throat was what worried me. Was it throat cancer or was it just some kind of deformity which had gone unnoticed before? All these qualms niggled my mind relentlessly, but I did not visit a doctor.

Clothes started getting tighter, my face looked puffy in pictures, the sparkle had gone in my eyes and in my spirit. My self-confidence and sense of self worth were also getting snuffed out. Yet, for inexplicable reasons, I did not visit a doctor. To this day, I cannot justify this to myself and less to anyone else. The internet remained the source of remedy to all my ailments and I trudged on.

Getting up in the morning was a Herculean task; bathing the children, feeding them, keeping up with their daily activities burned me out. By nightfall, I was a zombie. My husband would look forward to movie nights at weekends. The better part of my intelligence was put to work in figuring out ways to stay awake, to keep the drooping eyelids propped open, or to merely find a position in which I would not be noticed dozing off. I had not experienced this kind of lethargy in my entire life, and I was lost.

Until one day I finally mentioned the symptoms to a friend who encouraged me to go for a general checkup. The doctor took a mere three seconds to diagnose me: hypothyroidism. The tests showed an almost completely inactive thyroid gland. The doctor was surprised that my organs had not started shutting down. Thus began my journey to gain my spirit, my life, my relationships back.

I can taste the highs of life again; yet there are still those lows when I have to siphon every scrap of energy to function normally, but yes I have learned to cope, and to accept that I have to listen to my body and adapt my lifestyle accordingly. I was in fact lucky to be diagnosed before any permanent damage happened. One needs to stay very closely tuned to one’s health and body; a lesson I learned for life.

BTF comment:

If you are experiencing any of the symptoms described in this article, we advise you to visit your GP.
My story

Iga Cegielko

After she was diagnosed with hypothyroidism, photography student Iga created a photo montage of people’s necks

After three years of experiencing symptoms, such as weight gain, feeling cold, insomnia, anxiety and depression, I was finally diagnosed with hypothyroidism.

Although my symptoms are now largely under control, I wanted to raise awareness of the thyroid and its vital function in our bodies. So I came up with the idea of ‘Neck Selfie’ for my final year project. This was displayed in temporary exhibitions at The Borough Road Gallery and at Free Range in Shoreditch, London.

The montage of images represents how thyroid disease is often invisible, despite affecting up to one in twenty people in the UK. Fifteen of the photos are slightly elevated to symbolise the swelling of the neck and face, which can be indicators of a thyroid disorder.

‘Neck Selfie’ has raised awareness about thyroid disease to approximately 300 15-30 year olds who visited the shows. Visitors thought the photo montage was a good way to get people talking about this often hidden disease. It also prompted 10 people to consider testing their Thyroid Stimulating Hormone (TSH) levels, which is just great.

Why not share your story?

We know our members like to read about other patients’ experiences of living with thyroid disorders. If you would like to share your personal story of day to day life with a thyroid condition, please get in touch: editor@btf-thyroid.org or write to us at the address shown on the back page of BTF News.
Our brother Billy had the misfortune of being born with hypothyroidism before the introduction of routine blood tests (the heel prick test), which picks up this condition shortly after birth. As a consequence, his thyroid disorder remained undiagnosed throughout his childhood.

His symptoms were severe and persistent; his growth was restricted and his mental development was impaired. He was consigned to classes for what were then referred to as ‘backward children.’

Tragically, it was not until his early teenage years that Billy’s symptoms became so severe that he had to be admitted to hospital where he was diagnosed as hypothyroid and treated with the hormone, thyroxine, which he was unable to produce himself.

Although it was too late to reverse the negative effects of his condition on his mental and physical health, the treatment did lead to a rapid improvement in Billy’s health. He went from being unable to do much physical activity to running around bursting with energy. This really came home to us one day when he followed us up the apple tree in our back garden. We recall his excitement and joy in his face as he made the ascent the first time; to Billy it was his Everest.

Billy never blamed anyone for his condition and it didn’t prevent him from living his life very much on his own terms – he could be very stubborn!

Another major transformation in Billy’s life came when he began to attend a day centre in Southport in the early 1970s. With the support and encouragement of staff, Billy developed interests in cookery, pottery and writing.

Our brother also took a keen interest in current affairs, railways, science and technology and was especially interested in the NASA space programme. He followed their missions avidly on the internet and could be relied on to update us on their status at any time. As an acknowledgement to Billy’s interest in astronomy, his niece had a star named after him. We hope he might now meet his soul mate, Patrick Moore, and talk about the latest discoveries and future ambitions.

Comment from our medical advisor, Dr Salman Razvi:

One child in every 2000 – 3000 in the UK has congenital hypothyroidism (CHT). Most babies born with CHT look entirely normal and have no obvious symptoms. That is why it is so important that all children are tested at birth. Untreated, CHT can lead to impaired brain development.

The heel-prick test is taken in babies at five days old and has vastly improved the prospects for babies born with hypothyroidism. Upon diagnosis, treatment with synthetic thyroid hormone, levothyroxine, will be started straight away. The vast majority of children who are detected and treated promptly grow up normally. Medication is usually taken for life and children will have regular blood tests to ensure the dose is correct as they grow.
**Letters and comments**

**Brexit up-date**

**Our member asks:** Is there any update about the supply of thyroxine post Brexit? There is information coming from many recognised sources about the difficulties of generic supplies at present. I have an underactive thyroid and I am on levothyroxine.

**Our medical advisor replies:** Until recently we had no specific guidelines regarding this issue as reports about supplies were sporadic and still are to a large extent. We have recently received an update from the Pituitary Foundation on this matter. For patients on a 28 day repeat supply they would ‘always recommend an additional supply in case of illness or an unforeseen event.’

To organise a reserve supply you will need to make an appointment with your GP and request a one-off prescription for an extra two months (56 days) of levothyroxine.

**28 day prescription rule**

**Our member asks:** I want to join the merchant navy but I am concerned about the 28 day prescription rule.

I have had hypothyroidism my whole life and manage well on my daily medication. I have read that patients are only prescribed thyroxine for 28 days at a time. Will I be able to obtain an extended prescription for my thyroxine to enable me to travel?

**Our medical advisor replies:** I think it would be perfectly reasonable to ask your GP for a longer lasting prescription. GPs often do prescribe more than 28 days’ worth of medication, as it cuts down the number of visits the patient has to make and saves GP time. If you are a compliant at taking your medication then there should be no reason for your GP not to do this.

I also understand at the moment the GP can issue a cross border prescription for use in another EU country. With the Brexit issues this may not be possible for much longer however. I would advise you check this out.

**Feeling isolated by thyroid disorders**

**Our member asks:** Since being diagnosed with thyroid eye disease, I have felt very isolated. My eye clinic is 40 miles away. I also don’t go out anymore due to my poor health. When I do, no one recognises me due to the lumps and swelling in both eyes and weight gain. This is very depressing.

**Our medical advisor replies:** We are sorry to hear you are having such a hard time and your symptoms do sound quite severe. If you would like to access more support, we have a closed Facebook group for patients with thyroid eye disease. Here you can share your experiences with other thyroid eye disease patients.

Alternatively, we have a network of telephone contacts. These volunteers all have experience of various thyroid disorders and patients often find it really useful to chat through their concerns with them. Contact details are available here https://bit.ly/2UmAMvL

Despite the distance involved travelling to your eye clinic, you really do need to be seen by a specialist and preferably an endocrinologist and ophthalmologist together, as only seeing a GP would not be sufficient for your needs.

**Iodine dye in scans**

**Our member asks:** I am on carbimazole for my hyperthyroidism. Will the iodine dye being used in my CT scan for heart problems cause any issues?

**Our medical advisor replies:** You are correct that patients with hyperthyroidism are generally advised to avoid products high in iodine, such as iodine supplements. As your Graves’ disease is being controlled with the antithyroid drug, carbimazole, it is unlikely to cause any issues.

The problem usually occurs when hyperthyroidism is untreated, or unsuspected, in patients. The iodine dose used in coronary angiopathy scans is much lower than those used in other CT scans such as chest, abdominal and pelvis scans. I would suggest you have a thyroid function test one week after your scan as a precaution, as this is when it would most likely be an issue.

**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,
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or by email to medical-query@btf-thyroid.org.

Your letter and our reply may be published in the newsletter. All medical queries will be anonymised.

Medical questions 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.

Where we publish links to online resources, hard copies are available from the BTF at the address shown on the back cover or by contacting us info@btf-thyroid.org.
Thyroid diet advice

Our member asks: I have an underactive thyroid that was first diagnosed about 10 years ago. However, I didn’t start medication until 2012, when I was also diagnosed with rheumatoid arthritis.

I am a little confused about which foods should be avoided and ones that are beneficial. Please can you advise me what I should and shouldn’t be eating?

Our medical advisor replies: Sadly, there is no real magic diet for thyroid disorders but some foods do make the medication less effective and there is little advantage in consuming some other foods.

For example, levothyroxine is best taken on an empty stomach with water.

If you are taking other medication for your arthritis these may contain elements that may decrease the effectiveness of your levothyroxine so it is wise to check with your pharmacy.

Grapefruit, on the other hand, will increase absorption of levothyroxine.

Weight gain can be a problem for patients with underactive thyroid but a well balanced diet and exercise can help maintain a steady weight for most people.

You mention certain foods that trigger your rheumatoid arthritis so you may wish to eliminate these. Soya is known to interfere with thyroxine absorption. So if you do take soya products you should leave as long a gap as possible between taking the medication and eating the produce.

A Mediterranean type diet is often recommended for patients with rheumatoid arthritis and this often works well for thyroid patients also.

Further information can be found on our thyroid and diet factsheet https://bit.ly/2GOE46B

Medical comment

Could antipsychotic drugs affect thyroid function?

Following recent reports in the media that patients being treated with antipsychotics for mental health disorders are more likely to develop a thyroid disorder, our medical advisor Dr Salman Razvi writes:

Abilify or aripiprazole is an antipsychotic drug that works by influencing the levels of the chemical messenger dopamine in parts of the brain that are associated with psychosis. The exact mechanism of how aripiprazole works is not fully understood. However, like most drugs in this group, it is associated with a number of side effects. Some of these are similar to the known symptoms of an underactive thyroid such as weight gain, tiredness etc. Studies have shown that aripiprazole can lower the thyroid hormone thyroxine by very small amounts and doesn’t have an effect on the pituitary hormone TSH. The reduction in thyroxine is minimal and unlikely to have any impact on how a person feels.

Lithium is another drug used in psychosis and is considered as a gold standard treatment for bipolar disorder. But, its use is limited by the potential for toxicity (and hence the need to monitor its blood levels) and the number of side effects it can have including effects on thyroid function. Important mechanisms of the effect of lithium on the thyroid gland is that it reduces the release of thyroid hormone from the thyroid gland and also reduces thyroid hormone production.

Approximately 1-2 people out of ten treated with lithium will develop an underactive thyroid. Therefore, health professionals usually monitor thyroid function via blood tests on a regular basis in people who are prescribed lithium therapy. The risk of developing an underactive thyroid is more common in people who may have a family history of thyroid disease and/or may have positive antibodies against their thyroid gland. However, some of the side effects of lithium – mainly weight gain – are very common and usually unrelated to its effect on thyroid function.

In a number of individuals, the effects of lithium on thyroid function will improve if the lithium is discontinued but this is not always the case. However, this decision should be made only after discussing with the health professional concerned as often the benefits of lithium on managing the psychosis outweigh its impact on the thyroid gland and hormones – which can be relatively easily managed.

Did you know?

Last year our medical letter coordinator, Lorna Pankethman, replied to over 700 medical enquiries with the help of our volunteer medical advisors. The BTF is the only UK thyroid support organisation offering this service and it is highly valued by our members. Here are just some of the positive comments we have received recently:

Thanks so much for getting back to me so quickly. It has reassured me a lot!

Since my thyroid disorder took a long time to be diagnosed, it made me a bit concerned about things being missed. This service is really valuable, with all the different information online and the difficulties in seeing a GP it can be easy to get confused about thyroid related issues.

Thank you so very much for your help, reassurance and further information for me to look at before I see the specialist.
Iodine
The Royal College of Obstetricians and Gynaecologists is preparing guidelines on the Management of Thyroid Disorders in Pregnancy, as an aid to good clinical practice. Topics covered are:

- Thyroid function tests in pregnancy
- Hypothyroidism
- Hyperthyroidism/Thyrotoxicosis
- Thyroid antibodies and miscarriage and preterm delivery
- Thyroid nodules and thyroid cancer
- Postpartum thyroiditis
- Screening for thyroid disease during pregnancy
- Iodine and supplementation in pregnancy

The section on iodine and supplementation in pregnancy will look at the impact of severe iodine deficiency on the mother and baby, the iodine status of pregnant and breastfeeding women in the UK. It will also look at the evidence that iodine supplementation in pregnancy and breastfeeding improves outcomes in severe and mild deficiency for those with a normal functioning thyroid.

Recommendations for daily iodine intake for women planning pregnancy, pregnant women, and those who are breastfeeding will be covered as well as advice on how to achieve the recommended daily intake.

In preparation for the release of the Guidelines later this year, the UK Iodine Group (UK) is working with consultant obstetrician and gynaecologist Mr Michael Marsh, member of UKI and developer of the Guideline to ensure that health and medical professionals, as well as the general public, are aware of the importance of iodine and receive appropriate information.

Thyroid Eye Disease Project
Janis Hickey & Lorna Pankethman of the TEAMeD Operational Group provide an update of this project initiated by the Thyroid Eye Disease Amsterdam Declaration:

Our thyroid eye disease (TED) project – TEAMeD-5 – has evolved from the collaborative work carried out for several years by the BTF, TEDct and representatives of professional organisations with an interest in TED. Working with the British Oculoplastic Surgery Society (BOPSS) we are now rolling out TEAMeD-5 across the UK with the aim of improving treatment and care for TED patients.

Fifteen experienced endocrinologists have taken up the position of regional leads and are preparing to implement the plan in their hospitals, and subsequently to cascade the information to local hospitals in their trusts.

Elements of TEAMeD-5:
1. DIAGNOSE Graves’ accurately (e.g. using thyroid antibody testing) to identify patients at risk of TED
2. SCREEN all patients with Graves’ disease for early symptoms and signs of TED
3. ALERT patients with Graves’ disease to the early symptoms of TED using a TEAMeD early warning card
4. PREVENT – reduce the incidence of TED in Graves’ disease by smoking reduction, early induction and maintenance of euthyroidism and avoidance of radioiodine in active TED
5. REFER – prompt referral of patients who develop TED directly to a regional multidisciplinary clinic with extensive experience of managing TED

In brief
Sometimes it can be hard to keep up to date with what is new in research and treatment for thyroid disease. This new column brings you some of those latest developments in bite-size form.

Lactose and additive free levothyroxine
The manufacturer of lactose and additive free levothyroxine, Martindale Pharma Company, is now an Ethypharm Group company. Where you have a repeat prescription for this medication, we advise you ask your GP to change your prescription to the new supplier, which can then be forwarded to your nominated pharmacy. Contact details for Ethypharm are:
connect@ethypharm.com
01628 551900
www.ethypharm.co.uk

NICE Guidelines
As reported in issue 97 of BTF News, BTF volunteers and patients contributed to the consultation process as part of the development of the first ever NICE guidelines on thyroid disease. These will aim to improve the diagnosis, management and follow-up of people with thyroid disease.

The guidance is expected to be published in November 2019. You can follow progress of the guidelines at https://bit.ly/2FUpmKw

Treatment of pregnant women with levothyroxine where antibodies are present
Researchers have published the results of a study which was supported by the BTF and its members. Thyroid Peroxidase (TPO) is an enzyme normally found in the thyroid gland, which plays an important role in the production of thyroid hormones. Antibodies against TPO are associated with an increased risk of miscarriage and premature delivery, even when thyroid function is normal (euthyroid).

A trial named TABLET (Thyroid AntiBodies and LEvOThyroxine) investigated whether treatment with levothyroxine would increase live birth rates among euthyroid women who had positive TPO antibodies and a history of miscarriage or infertility.

The conclusions were that the use of levothyroxine in euthyroid women with TPO antibodies did not result in a higher rate of live births. Details of the results of the trial are published in an article in the New England Journal of Medicine. https://bit.ly/2UbXXE

More information is available on the trial website.
www.birmingham.ac.uk/TABLET
Coping with fatigue

Feeling tired or experiencing fatigue are common symptoms of some thyroid disorders. In the first of our regular new ‘Coping with’ features, we offer some tips and advice on how to manage fatigue.

The words tiredness and fatigue are often used to refer to the same physical feelings in general conversation. For anyone who has ever experienced fatigue, it is totally different from tiredness. While a good night’s sleep will usually resolve your tiredness, fatigue will not just go away overnight.

Feelings of tiredness and fatigue are a common symptom of some thyroid disorders and we are frequently contacted by patients who are struggling with day-to-day life because of it. One member describes fatigue as: Feeling constantly drained, sometimes to the point where I cannot physically move. Another member living with Graves’ disease says: I used to get home from work and fall asleep almost immediately.

There are many reasons for experiencing tiredness and fatigue. In patients with an underactive thyroid (hypothyroidism), the body’s metabolism slows down. This can often lead to many symptoms, including lethargy and fatigue. In patients with an overactive thyroid (hyperthyroidism), the body’s metabolism speeds up. This overactivity can lead to fatigue as well as difficulty sleeping.

Where daily hormone replacements tablets, such as levothyroxine, are prescribed for an underactive thyroid, symptoms including fatigue should gradually begin to disappear. Similarly, patients receiving anti-thyroid drugs for an overactive thyroid should begin to see an improvement in their energy levels.

I am taking my thyroid medication but still feel tired all the time.

Frustratingly, in some patients feelings of fatigue can persist for some time after they have commenced their medication. Some of the following tips may help your medication to work more effectively:

- Take your medication consistently every day as failure to do this can affect your blood test results and your health.
- If you forget to take a dose, take it as soon as you remember.
- Antithyroid drugs for hyperthyroidism can be taken either consistently with meals or on an empty stomach.
- To aid the effectiveness of levothyroxine try to swallow your tablets with water on an empty stomach and avoid eating for 30 minutes afterwards.
- It is also best taken at least four hours apart from calcium, iron, cholesterol-lowering drugs (cholestyramine, colestipol), and multivitamin tablets that contain iron, as these can decrease absorption. Grapefruit, on the other hand, is known to increase the absorption of levothyroxine as it increases acidity in the stomach.
- If you wish to take soya, there should be at least a four hour time interval between consuming the soya products and taking levothyroxine, as it interferes with its absorption.
- It is always advisable to tell your doctor if you are taking any other medicines, supplements or special foods as some can interfere with levothyroxine absorption.
Coping with fatigue

Can following a special diet boost my energy levels?
When feeling low in energy levels, it is tempting to reach for sugary snacks. Whilst these can boost your energy levels temporarily, the surge in energy is often followed by a dip making you feel worse again. By replacing sweet treats with healthier options, including proteins such as lean meat, fish, eggs and fats contained in avocados, nuts and seeds, you can help balance your blood sugar levels.

Avoiding or reducing caffeine can help with your sleep and may make you feel less tired. Reducing alcohol levels may also improve your sleep quality.

If you have hypothyroidism or hyperthyroidism you are advised to avoid preparations and supplements high in iodine as it can make the condition worse.

Similarly, avoid products such as kelp, as they may interfere with thyroid function & wellbeing. Kelp is derived from seaweed and is naturally high in iodine. Because of this it is sometimes marketed as a ‘thyroid booster’ and can be purchased in dry preparations and tablets. As with iodine itself, it is of no health benefit to those with thyroid disease, and in the case of hyperthyroidism may aggravate your symptoms, including fatigue.

I’m tired but I still can’t sleep at night
When we are feeling tired all the time, sleep can become an obsession yet it often evades us. Some of the following tips may help you to improve your quality of sleep:

● Introduce a bedtime routine. By having a bath or reading a book before bed, this can help you unwind.

● Avoid electronic devices – try to turn off electronic devices at least an hour before bedtime and do not keep them next to you in the bedroom thus reducing the temptation to look at screens.

● Try to keep regular sleeping hours so the body’s sleeping patterns do not become confused.

What about exercise?
It may not seem to be common sense to use up precious energy levels by exercising. However, exercise can improve both your energy levels and mood. Exercise does not need to be vigorous and often activities such as yoga and meditation can help you to relax.

It’s all getting too much for me. What can I do?
It’s easy to feel overwhelmed when you are lacking in energy. The following tips may help you to manage your fatigue better:

● Prioritise your tasks – are there some things that can wait or you can ask someone else to do? Perhaps starting with the smaller tasks can make things seem less overwhelming.

● Organise your living space so it works for you – by making practical changes in the home or work place, you may be able to save your energy. For example, could moving appliances around save you having to get up and down repeatedly?

● Rest – building rest into your day can help you to manage your fatigue. With a bit of trial and error, you can establish what rest patterns work best for you.

Where symptoms of fatigue persist, we would recommend you see your GP. Further information is available here:
https://bit.ly/2Jo0YBB
Our local groups provide the opportunity to meet with others who have a thyroid disorder and to learn tips and advice about how to manage your condition.

Before attending a meeting or event, please check the BTF website for the latest details to ensure it hasn’t been cancelled. www.btf-thyroid.org

**Bristol**

About: The group meets on the second Wednesday of each month 7pm-9pm. 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

**Cambridge**

Past meeting: 16 March 2019

We were joined by David Halsall, Consultant Clinical Scientist & Director of the specialist endocrine testing laboratory at Cambridge University Hospitals Trust who gave an entertaining and informative talk about thyroid function tests (blood tests). Many of us didn’t realise the seasonal importance of thyroxine which causes tadpoles to change into frogs. David also answered lots of questions we had on thyroid testing. Thank you to David for giving up his Saturday morning to meet with us.

Location: Eddington Community Centre (Storey’s Field Centre), Cambridge CB3 1AA

Next Meeting: TBA. Please check the BTF website for further details.

Contact: Mary on 01223 290263 or email butterflyecho@hotmail.com

**Leeds (Wharfedale)**

Next meeting: September – Date – TBA

Speaker: Dr Sam Pearson

Location: The location varies for each meeting. Please get in touch for details.

Contact: Caroline on 0113 2886393 or email: cfields237@btinternet.com

**Milton Keynes**

About: The group meets three times a year in March, June and October.

Regaining Full Health Following Thyroid Disease’.

Ellen covered the lifestyle elements important for health and wellbeing. These included regular eating and sleeping times, as well as healthy eating.

Our members really enjoyed the meeting and will be inviting Ellen back to future meetings to discuss the importance of supporting the gut and the link between gut bacteria and the brain.

Location: Liberton High School, Gilmerston Road, Edinburgh EH17 7PT.

Contact: Margaret Tel: 0131 6647223 or email: M2mgregor@aol.com

**Edinburgh**

About: The Edinburgh group meets on the last Tuesday of each month except for school holidays. The meeting is usually a ‘drop-in’ session and anyone is welcome between 7.15pm and 8.30pm to discuss their particular thyroid condition and to get information and support.

Past meeting: At our February meeting, registered nutritional therapist, Ellen Spinner, spoke on the topic ‘A Nutritional Strategy for

Professional speakers with a health related background attend each meeting. Meetings take place from 10:30 to 13.00. A voluntary donation of £2.00 is requested to cover the cost of room hire.

Past meeting: Information event, 2 March 2019

Following on from previous member feedback, we held a more informal session in March. To allow everyone to take part, members were divided into two smaller groups. We covered numerous topics in our groups which allowed for exchanging ideas and information. The new members who joined us stated:

‘Learned a lot from the friendly, helpful people – I felt relaxed and easy to talk.’

Next Meeting: 12 October 2019. Join us to meet representatives from the BTF’s head office.

Speakers: Cheryl McMullan – CEO Operations and Julia Priestley – CEO Development

Location: The Pavilion, Open University, Milton Keynes MK7 6AA

Contact: Wilma on 01908 563289 or see www.thyroidmk.co.uk, find us on Facebook or follow us on Twitter @ThyroidMK.

**Start a support group!** Could you share your experiences with thyroid disorders to help others? To find out more about setting up a support group, please email info@btf-thyroid.org

[Volunteer]
BTF LOCAL COORDINATORS
Our voluntary local coordinators organise meetings but will also take calls on thyroid disorders they have experienced. Please see the key below.

Bristol – Michelle (U)
michelle.griffiths@live.uwe.ac.uk (for local group information only)
Cambridge – Mary (O,RI,U)
brutterflyecho@hotmail.com 01223 290263

Milton Keynes – Wilma (U) 01908 563289
Edinburgh – Margaret (PC) 0131 6647223
Leeds (Wharfedale) – Caroline (O,U) 0113 2886393

BTF TELEPHONE SUPPORT CONTACTS
Our telephone contact volunteers take calls on thyroid disorders they have experienced. Please see the key below.

Dave (PC,CS,RAI) 07939 236313
Jackie (PC,CS) 01344 621836
Gay (G,TS) 0208 7359666
Angela (U) 01943 873427
Karen (U) 01628 529212
Ann (GR,RI,TS,TED) 01642 300709
Maria (U) 0208 7934360
Jenny (PT) 07413 360886
Joan (U) 01392 874517
Jane (GR,RI,TED,G,U) 01737 352536
Peter (TED,GR) 01200 429145
Penny (Ch) 01225 421348
Kellie (C) 07725 726800
Kate (Ch) 07791 007673

KEY
● 2-5pm Mon, Tues and Thurs ● after 6pm weekdays and anytime weekends ● 2pm-5pm Wed and Fri afternoon
● 10am-2pm Mon-Thurs ● 9am-5pm weekdays, 10am-5pm weekends ● 7pm-9pm weekdays, 10am-7pm

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

Ch Thyroid disorders in Children
PT Postpartum Thyroiditis
PC Papillary Cancer of the thyroid
CS Thyroid Cancer Surgery
RAI Radioactive Iodine (1-131) Ablation
G Goitre
TS Thyroid Surgery (non-cancer)
U Underactive thyroid
O Overactive thyroid
GR Graves’ disease
RI Radioactive Iodine treatment for an Overactive thyroid
TED Thyroid Eye Disease
C Thyroid Cancer

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@irishcancer.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

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<td>Members living overseas</td>
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Concession: if you are unwaged you may wish to pay the concessionary rate. Please help us by ensuring that you pay the correct subscription.