The largest Europe-wide study into iodine deficiency starts

Iodine deficiency is the most important risk factor for thyroid disease in adults and children. Thyroid disorders are frequently found in cases of iodine deficiency. Pregnant and nursing women in particular have an increased need for iodine in order to provide enough thyroxine to ensure optimal development of their child. Even a slight iodine deficiency during pregnancy can lead to impaired brain development of the child, consequently reducing intelligence. In fact, iodine deficiency is the world’s leading cause of preventable brain damage and for years the World Health Organization (WHO) has warned that Europeans are increasingly affected by the consequences of iodine deficiency.

Lack of uniform data

Professor Henry Völzke, from the University of Medicine Greifswald, is the coordinator of EUthyroid and has been instrumental in pushing the project forwards. He says ‘Currently in Europe there is no uniform dataset for iodine intake. Therefore, we can only speculate about the magnitude of health problems resulting from a deficient iodine intake.’ The EUthyroid network is gathering for the first time uniform data on the iodine intake of the population in participating countries. It will compare national measures and dietary habits and work out appropriate measures to improve iodine intake in Europe.

In principle, iodine is absorbed naturally through the diet. There are, however, many countries across Europe that, owing to their continental location and dietary habits, are iodine deficient (seafood is a good natural source of iodine so mountainous regions typically have particularly low levels). Over the last century many European countries have introduced prevention programs by ensuring salt used in the food industry is iodised therefore improving the iodine supply to the population. However many prominent countries in Europe, including the UK have not introduced iodisation programmes. Consequently the WHO has for years called for a review of the situation in Europe through uniform monitoring as a basis for improved preventive measures. ‘Europe has a lot of experience with the harmonisation of different processes across national borders, but in the prevention of iodine deficiency we are lagging behind significantly’ said BTF Patron Professor John Lazarus from Cardiff University, regional coordinator of the Iodine Global Network (IGN) in Western and Central Europe, and EUthyroid partner. ‘I trust that with EUthyroid a dynamic is created which leads to significantly more effective preventive measures.’

See page two for frequently asked questions on iodine.
FAQs on iodine and thyroid patients

Although those in the UK without a thyroid condition need to increase their intake of iodine, particularly pregnant women, to avoid potential problems with their and their unborn child’s thyroid function, people with a pre-existing thyroid condition have different requirements. To try and help clear up any confusion, here are a few of the most common questions we receive at BTF HQ along with answers from the UK Iodine Group regarding iodine intake:

Is there any benefit in taking kelp (iodine) supplements when you have a thyroid disorder?

High dose iodine preparations such as kelp can lead to both hypo- and hyperthyroidism in susceptible individuals with an underlying thyroid disorder so are best avoided.

I have been told by my doctor that I have a borderline thyroid disorder. Will kelp/iodine supplements help me?

Kelp or iodine supplements will almost certainly not help anyone with a borderline thyroid disorder because the disorder is probably an autoimmune condition. In fact iodine supplements or kelp could make things worse.

I’ve just been diagnosed with hypothyroidism, should I be taking iodised salt/iodine supplements?

There is no value in taking extra iodine if you are on levothyroxine as you are receiving manufactured hormone ready made without needing the raw material to make it yourself.

I know that taking iodine is beneficial for the three months prior to pregnancy, but is it possible to take too much?

For those with pre-existing hypothyroidism no additional iodine is required. They need to ensure that they have adequate replacement of their thyroid hormone pre-conception and ensure this in pregnancy particularly in the first trimester when they may require between 25-50mcg extra of levothyroxine daily. They should see their GP as soon as they are planning or get pregnant.

Pregnant women with an over-active thyroid disorder should also see their GP when they decide to try to conceive or as soon as they find out they are pregnant as they may need to alter their medications. Go to www.btf-thyroid.org/projects/pregnancy for more information.

The current recommendation for those who have no history of a thyroid disorder is that for the three months prior to pregnancy and during the pregnancy they should ensure adequate iodine intake. Go to www.ukiodine.org

Seaweed and the thyroid

Seaweed has recently been advocated as the new ‘super food’. Whilst seaweed is a very good source of vitamins and minerals, some types of seaweed, particularly brown seaweed (Kelp or Kombu) contain very high levels of iodine and should be avoided, particularly by those with an overactive thyroid. Pregnant women and children with a normal functioning thyroid should also avoid eating it because of the amount of iodine it contains. Professor Margaret Rayman, Professor of Nutritional Medicine, University of Surrey and member of the UK Iodine Group, speaking to the Food Programme on BBC Radio 4 in May (www.bbc.co.uk/programmes/b05sv6y) explained how eating eight grams of brown seaweed a day would give an individual over 20 times the recommended safe level of iodine. She also talked about recent large-scale studies in Asia linking over consumption of seaweed with an increase in thyroid cancer and is urging caution in the use of this powerful plant.

www.ukiodine.org

www.btf-thyroid.org/index.php/campaigns/iodine
News from BTF

Code of conduct
Following recent news reports on the mis-selling of personal data by prominent charities, we would like to reassure all our members and fundraisers that the BTF never passes on any personal details to third parties. We are currently reviewing all our communication procedures to ensure we continue to comply with best practice recommendations.

BTF annual report online
The latest annual report for the BTF is now available on the Charity Commission’s website or click on http://bit.ly/1VG9kZg

BTF poster UK-wide campaign
One of the ongoing frustrations that we know patients have is the lack of information given to them by their GP. Raising the profile of thyroid disease amongst GPs remains one of the BTF’s highest priorities. We were therefore delighted to have the opportunity for one of our BTF posters to be distributed as part of a Practice Managers Information Pack which was sent out to 10,000 GP practices (96.7% of UK surgeries) at the end of September. We are hoping that this will mean that many more patients will find out about the BTF’s highest priorities. We were very grateful to our team of medical experts who helped prepare this comprehensive information to help patients. Questions cover TSH reference ranges, combination T3 and T4 therapy, pregnancy and alternative therapies. Go to: www.btf-thyroid.org/professionals/106-statements

Tell us what you want from the BTF
The BTF Trustees are in the process of developing a plan that will help define the charity’s priorities and confirm the direction and key objectives during the next five years. You are invited to get involved in this process by completing the short survey that is enclosed with this newsletter. You can also complete the survey online by going to www.btf-thyroid.org/get-involved/201-surveys. The deadline for feedback is 15 January 2016. Once the planning process is complete we will report back to members through this newsletter.

Order your BTF Christmas cards
We have a brand new collection of traditional and contemporary Christmas cards for sale, which will raise valuable funds for the BTF and let people know about our work.

You can order your cards now by filling in the flyer enclosed with this newsletter or by visiting the BTF website. Cheques should be made payable to ‘The British Thyroid Foundation’ and sent to the address on the order form.

Chronic illness survey
Sabine Topf, a postgraduate student in Psychology at University College London is doing her PhD on chronic illness and wants to research what people with a long-term condition think about their illness, including their experiences with illness and treatment in the recent versus distant past, their knowledge about treatment options and reactions of family, friends and colleagues when they learned about the illness. The aim is to gain further insight into how to provide better support for patients in the future.

Go to http://tinyurl.com/illnessexperience to take part in this independent survey. It takes about 40 minutes (30 minutes for Part 1, and 10 minutes for Part 2 four weeks later). Participants will receive a £3.75 Amazon voucher for a completed survey. All adults (18+) who have been diagnosed with a chronic illness and have been prescribed medication are eligible to take part.

Survey on hypothyroidism and fatigue
Dr Nikki Coghill from the Centre for Academic Primary Care (CAPC) at the University of Bristol is currently writing up the results from her recent survey on hypothyroidism and fatigue (as mentioned on page 2, BTF News 87). We hope to make these available early next year.

Q & As to accompany the British Thyroid Association Statement on the Management of Hypothyroidism now available
Following the publication of the new statement on the management of primary hypothyroidism by the British Thyroid Association (BTA) (see page 1, BTF News 89), the BTF has now prepared a list of Q & As with both short and long answers. We are very grateful to our team of medical experts who helped prepare this comprehensive information to help patients. Questions cover TSH reference ranges, combination T3 and T4 therapy, pregnancy and alternative therapies. Go to: www.btf-thyroid.org/professionals/106-statements

New BTF website launched
The BTF website has had an overhaul to give it a responsive, clean layout that looks great on all devices from large monitors to iPads and smart phones. The website is still packed full of information on a wide range of thyroid disorders, the latest research news, practical advice sheets and fundraising success stories but is now simpler to navigate and easier to view on smaller screens. Our webmaster Claire Skaife says, ‘We transferred all the old articles (over 250 of them) to the new site and cleaned it up. Having worked on the site since its last update in 2010 I’m very familiar with what’s on there, but I couldn’t have done it without the rest of the team who helped review every word we’ve written in the last five years. The new update means the BTF website will be a great resource for years to come’.

Comments from our beta testers have been very positive: ‘Love the new crisp clean layout on my iPad!’ ‘Really easy to find information’. ‘Lots of useful info. Fantastic!’ ‘Feels fresh and modern.’

To see our new look head over to www.btf-thyroid.org and let us know what you think.
 Armour thyroid and Hillary Clinton

The UK press, including the *Daily Mail* (31 July 2015), widely reported on the disclosure by Hillary Clinton’s doctor in the *New York Times* that Mrs Clinton takes Armour Thyroid to treat her hypothyroidism. Armour thyroid (also known as desiccated thyroid extract or NDT) is a thyroid hormone preparation made in the USA from dried extracts of pig thyroid gland.

**Mark Vanderpump,** President of the British Thyroid Association (BTA) comments: ‘In the USA, as in the UK, levothyroxine (or synthroid) is the treatment recommended for people with hypothyroidism, so this is an unusual choice by Hillary Clinton’s doctor. NDT is not licensed as a medicine in either the UK or the USA but classified by the Food and Drug Administration (FDA) as a whole-food dietary supplement. As detailed in the recent BTF Q&As (see page 3) on the revised Management for Primary Hypothyroidism statement produced by the BTA, which has been published in *Clinical Endocrinology,* there is no evidence at present from clinical trials to suggest NDT is a more effective treatment for hypothyroidism. NDT contains one part of tri-iodothyronine (T3) to four-five parts of levothyroxine (T4); this compares to a T3/T4 ratio of about 1:14 in the human thyroid so it cannot be described as physiological or natural. Treatment with NDT may increase the long-term risk of problems of overtreatment from the excessive T3 including irritation of the heart resulting in tachycardia and loss of bone density and increased fracture risk.’

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**Out and About**

**Janis Hickey,** representing the BTF and **Julie McLaren,** representing the Thyroid Eye Disease Charitable Trust (TEDct) were invited to the Oculoplastic Allied Health Professional Study Day in London in September.

The emphasis of the meeting was on caring for patients who had undergone surgical procedures and treatments for a range of eye disorders, from both a nursing and counselling perspective. Presentations with particular relevance to thyroid eye disease included ‘Counselling the Oculoplastic Patient’ and ‘Orthoptics Assessment of TED’.

We would like to thank Nicola Dunlop, Oculoplastic Nurse Consultant at Moorfields Eye Hospital (MEH) and winner of the 2013 BTF Nurse Award for organising the meeting and inviting our patient support groups. It was an opportunity for us to raise awareness of thyroid eye disease, and the work of TEAMeD, in particular the recently published guidelines for thyroid eye disease (see page 5 *BTF News 89*).

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**BTF Projects Update**

The BTF is involved in several key thyroid related areas, with the aim of improving knowledge, assisting with research and improving the patient’s experience. At the moment we are focusing on developing a hypothyroidism care strategy, iodine deficiency and subsequent thyroid problems, children with thyroid issues, thyroid cancer and thyroid eye disease. Each project group meets regularly to discuss progress, although we do not always have updates available for every newsletter.

**Hypothyroidism Care Strategy**

**Professor Scott Wilkes,** member of the BTF Hypothyroidism Care Strategy group and leading clinical academic at the University of Sunderland is spearheading a ground-breaking new study into hypothyroidism called CATHRINE Clinical And genetic determinants of THyroid hormone Replacement IN general practice.

He is leading the team looking at control of hypothyroidism in general practice. Professor Wilkes is also working with researchers in Newcastle, Dundee and Wales to examine the effect that behavioural and genetic influences may have on its effective treatment. The BTF will help ensure the study remains patient focused by being involved in the design of the questionnaire, the accompanying literature and the practicalities for patients taking part. The study will examine why standard treatment is not as effective for all hypothyroid patients, and whether genetics plays a part in this, as well as behavioural factors.

As a Professor of General Practice and Primary Care embedded in the Sunderland School of Pharmacy, Professor Wilkes has unique opportunities to work with medical experts. As well as working at the University of Sunderland – which has the biggest School of Pharmacy in the UK – he is a part-time GP in Amble, Northumberland. He believes more needs to be done to highlight the condition and the effects it has on

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**Society for Endocrinology**

**British Endocrine Societies conference**

The BTF will be attending the annual British Endocrine Societies (BES) conference at the beginning of November in Edinburgh (as we go to press).

This conference is the largest UK meeting on hormone research and it includes some of the best British and international science and research, clinical investigation and clinical practice in endocrinology.

There will be a number of sessions on the latest treatments and debates concerning the thyroid, we’ll include a report on our website after the meeting.
people’s lives. He explained: ‘Hypothyroidism affects approximately three million people in the UK. But the symptoms can be very non-specific, ignored by patients and missed by professionals’.

‘Our study will look to see what can be done to treat the condition more effectively and to look at why, despite the treatment, some patients still feel unwell. Is it to do with lifestyle, genetics or both?’

He added: ‘We know that a significant proportion of people, who have been diagnosed with hypothyroidism and are being treated, still report ill health. Anecdotal information can be helpful to patients, but it is not a substitute for systematic and robust scientific evidence. Patients have the right to be able to distinguish between fact and fiction. It is important that doctors who specialise in thyroid disease better understand why a small proportion of treated patients don’t feel well. Paradoxically, a large proportion have fluctuating blood test results, leading to a lot of expensive rechecking, and the best way of addressing the situation is through rigorous scientific research’.

The project will also explore patient and professional attitudes and perceptions of symptom control in hypothyroidism. Patients will be interviewed and asked to share their experiences, the results of which were presented at the European Society for Paediatric Endocrinology meeting in Barcelona in early October. We hope to be able to report further progress on this project in the future.

Nurse Christine Davies of the Cardiff & Vale University Health Board, who is coordinating the project, writes ‘Thank you to all parents, nurses and doctors who very kindly took the time to complete the questionnaire on CHT. The comments received from all the parents were invaluable.’

**Thyroid eye disease**

*Thyroid* (the official journal of the American Thyroid Association) published a paper in September by members of the TEAMeD group (The UK Thyroid Eye Disease Amsterdam Declaration Implementation Group). TEAMeD was formed in 2010 to improve prevention, care and access to care for thyroid eye disease (TED), and comprises representatives of key organisations including the BTF. The article is entitled ‘Future research in Graves’ orbitopathy: from priority setting to trial design through patient and public involvement’. In the study the group reported on the two day Patient, Public, Professionals Information event on Graves’ Orbitopathy (GO) held in Newcastle in May 2014, which aimed to promote future research. The abstract explains how the highest priority for future research that came out of this event was for psychological support in GO, and prediction of GO.

www.ncbi.nlm.nih.gov/pubmed/26359308

In April 2015 TEAMeD submitted an application entitled Optimal Management of Patients with Graves’ Orbitopathy: Non-Specialist Assessment and Referral Pathways, to the Royal College of Physicians (RCP) which has been accepted on to the RCP Concise Guidelines Programme. This abstract outlined the recommendations for clinical diagnosis, initial management and referral pathways.

Further work is now being undertaken by TEAMeD to develop and disseminate the guidelines. http://bit.ly/1kgmQPR

**Iodine**

The UK Iodine Group, of which the BTF is part has put together a list of FAQs about iodine on their website www.ukiodine.org/FAQs They have also welcomed the news that the largest Europe wide study is to be undertaken on iodine deficiency (see page 1).

Recent international studies have been published on iodine deficiency. A viewpoint published in *The Lancet Diabetes and Endocrinology* by Zimmerman et al http://www.thelancet.com/journals/landia/article/PIIS2213-8587(15)00263-6/fulltext?rss=yes details the adverse effects of iodine deficiency in populations— decreased IQ, goiter, and hypo- and hyperthyroidism—and points out these are easily corrected with salt iodisation of food by the food manufacturers. Yet they continue to affect many countries, with an estimated 1·9 billion people at risk worldwide. Pregnant women are the key target group because iodine deficiency in these women can irreversibly impair cognitive development of the developing baby. Observational studies in Europe have suggested that mild-to-moderate iodine deficiency during pregnancy may have long-term adverse effects on child cognition. A recent Lancet series on child development, as well as the World Bank, recommend that governments put a high priority on salt iodisation to promote health and economic development. Although this recommendation was aimed at developing countries, it applies equally well to Europe.

Currently the amount and quality of information given to parents of newborns diagnosed with congenital hypothyroidism (CHT) varies enormously. Some parents receive very comprehensive support but others report that the lack of reassuring information and signposting leaves them feeling anxious and isolated at a time that should be so special. We are working with a small group of UK paediatric endocrine specialist nurses with the aim of producing a centralised accessible resource that will be available to all parents at the point of diagnosis.

So far we have hosted a short survey on the BTF website to gather data about people’s experiences, the results of which were presented at the European Society for Paediatric Endocrinology meeting in Barcelona in early October. We hope to be able to report further progress on this project in the future.

Nurse Christine Davies of the Cardiff & Vale University Health Board, who is coordinating the project, writes ‘Thank you to all parents, nurses and doctors who very kindly took the time to complete the questionnaire on CHT. The comments received from all the parents were invaluable.’
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 sponsorship forms, posters and other publicity materials. We can also supply BTF t-shirts or 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 photograph(s) along with your permission to publish them in the BTF News (subject to space) and on the BTF website.

Fundraisers

British 10k Runners

A record breaking 17 runners took part in The British 10k London Run on July 12 for the BTF. They were:


Jill Walters along with Graham and Jennifer (pictured together below) raised over £1,000 between them and had a fantastic time. Jill, who has an underactive thyroid, commented: ‘I have never run this distance before (age 58!) but apparently I was 98th in the over-50 age group women. We had a great run and we were even pleased with our times (not expected at all!’.

Debbie Webb has suffered with thyroid problems for the last four years and she wanted to do whatever she could to help people facing thyroid problems and thyroid cancer. She said: ‘The race day itself was tough and I was injured along the way but I managed to make it to the finish line in just under one hour and 23 minutes’.

Thank you to all our fantastic 10k runners for supporting the BTF!

To reserve a place in this year’s race on Sunday 10 July email fundraising@btf-thyroid.org

Jacqui Hoyle completed a 750m Open Water Swimming Challenge in a local lake for the BTF in July and raised nearly £250. Jacqui was diagnosed with Hashimoto’s Thyroiditis (autoimmune hypothyroidism) in 2013. Her motivation for taking on this challenge was to help overcome the physical limitations she’s encountered through living with fibromyalgia, which she believes is a symptom of having an underactive thyroid. She said: ‘Swimming has helped treat the muscle aches, stiffness and chronic pain’.

Amy and Matt Church ran the Jane Tomlinson York 10k in August for the BTF. Amy has a thyroid condition and has struggled to get the correct treatment. She really wanted to raise money to help people and families in the same position and they managed to raise £50.

Andy Handley ran the Birmingham Half Marathon in October (as we go to press)

Jalmeen Lall raised nearly £600 for the BTF by completing the Forsters Law Kent Coastal Marathon in September.

Anastasia Pinches and Julia Kirby both took part in the Tough Mudder Yorkshire event in August (a team-oriented 10-12 mile (18-20 km) obstacle course in case you were wondering!).

Julia (below) raised a fantastic £350 and said ‘The day was tough, muddy, tiring and very cold, but a great laugh with a real sense of achievement on completion. My favourite obstacles were Birth Canal, Cry Baby, Balls to the Wall and Pyramid! We’re planning on doing it again next year so it couldn’t have been too bad, either that or the brain fog has taken over and I can’t remember how bad it was!’

Anastasia (below) was diagnosed with an under-active thyroid at the age of 14. She raised over £250 and said ‘It was fun, tough and very, very muddy! I managed to finish it in around 4 hours (although I was surprised I finished it at all!) and was completely exhausted by the end! But knowing that all the money I’d raised was going to such a great charity spurred me on and I’m glad that I’ve managed to get the word out to my friends and family about the amazing work that the BTF charity do!’

Adrian Cobbin raised £470 by running the Great North Run after his dad was diagnosed with thyroid cancer last year. His employer Vocalink matchfunded his donation.

Tanya McLean ran the Norwich 10k in August and raised £100 for the BTF.
Cycling successes

Andy Sansom (below) cycled from Land’s End to John O’Groats in September for his 50th birthday and raised nearly £1,000! (What a way to celebrate!). He suffers from an underactive thyroid and wanted to give something back for the support he has received from the BTF over the years.

Glenn Pearce (right) also decided to take on this epic cycling challenge, he explains his reasons:

Deciding to cycle from Land’s End to John O’Groats has always been a lifelong goal of mine. I did this in the memory of my beautiful little big sister Tonie-Marie who sadly passed away three years ago, leaving six children behind and who herself had an underactive thyroid.

‘About two years ago I myself was also diagnosed with an under-active thyroid and so I have faced and still face the daily struggles that come with it. And so I took on this challenge with these additional challenges myself but I want to do so to not only achieve a personal goal of mine in my sister’s name whilst raising money and awareness of this debilitating condition and great cause, but to also give hope to all the people out there who believe they now can’t achieve their hopes and dreams because of this condition. My message is you can….trust me. I just cycled 934 miles in 12.5 days in spite of this condition!

‘If my example can inspire one person to strive to achieve their goals and dreams then I have succeeded. Live your life, follow your dreams and maybe you will surprise yourself if you just take the first step. You may have to do it differently to how you would have before you became ill but there is never only one path to your dreams and goals. Find the path that’s right for you and start heading towards it one step (or peddle in my case) at a time and you will get there.

I would not have smashed my £500 target, which is currently at £790, without the support I received and would like to thank my friends and family for all their encouragement, generosity and belief in me. I would also like to give a special thanks to the lovely employees of South Gloucestershire Council who donated and raised money on my behalf towards this necessary and worthwhile work that the British Thyroid Foundation do’.

Yvonne Wyllie who suffers from hypothyroidism took part in a 50 mile Pedal for Scotland event and raised £70.

Jason Mitchell (below) who has an overactive thyroid raised a fantastic £225 by cycling from London to Brighton in September.

Alicia Craven and Tiana Lever aged 11 held a cake and loom band stall at school. The girls raised an incredible £200 in total, split between the BTF and Alzheimer’s Society. Alicia suffers from an under-active thyroid and Tiana’s nan passed away from Alzheimer’s last year. Alicia also raised funds for the BTF by taking part in a fun run in the summer.

Roisin Sharp and her dad took part in the Mini Great North Run for the second year in a row – a distance of 1.5k and raised over £250! Roisin was born with an underactive thyroid and said her reason for taking part was to raise more money to help people with poorly thyroids.

Thank you so much girls!

Future Fundraisers

Steve Foulkes is cycling from London to Paris in September 2016 for the BTF. He explains his reasons: ‘Someone special to me went through thyroid cancer, whilst going through this she didn’t even stop work or being a mum and carried on as if nothing was wrong. She is now doing her bit to help others by taking part in a clinical trial. Whilst she was going through this I felt helpless but now understand that I can do something small to help raise money and maybe awareness, so I am going to be doing the London to Paris cycle ride in September 2016 and am hoping to raise £1500 for the BTF through my just giving page www.justgiving.com/steven-foulkes

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.

Employees of Capita collected £189.54 for the British Thyroid Foundation by taking part in a dress down Friday.

£47.20 was donated in memory of Ivy Besley.
My Story

August of 2014 my doctor felt a lump on the left side of my neck. She told me that this was a nodule and it was located on my thyroid gland. I had never thought too much about the thyroid before. Once the lump was discovered I had to go to multiple endocrinologists. I had my neck examined and I had many biopsies done on the area. My doctor told me that a lot of people live with nodules on their thyroids and that it doesn’t always mean that it will be cancerous. There was a 5% chance that this nodule would be cancerous.

On September 23 2014 I found out the results from my biopsies and was told that I had thyroid cancer. When the doctor told me, it felt like someone had ripped my heart out. I felt as though the world had stopped for a second. The first thing I thought was, ‘Will I make it through this?’ It was harder for me to accept this because I have struggled with health issues in the past. I had this piercing feeling in my stomach and I couldn’t help but think, why me? Why did I have to go through pain and sorrow again?

When I found out that I was able to beat this it really made me think about the people who can’t get through cancer and who fight so hard but sadly lose their lives. I wonder how is that fair? I have had so many emotions about this whole experience but I have more emotions about the people that can’t be helped. Going to countless doctors and cancer hospitals made me realise how real this is and how tough those cancer fighters are. When I found out I had cancer, I cried and cried and cried. I cried because this was happening to me, but I also cried because I could get through it. I cried for the people who had to lose their lives to this disease. I cried for their families who had to watch their loved one struggle. I cried for my family, because no parent should have to see their child suffer. I cried for my health, because I have fought for it multiple times. I cried to stay strong, no matter what.

My family means the world to me. They have truly been the best support system and I am forever thankful for their never-ending love. It was so hard for me to tell my family when I got the news. I remember shaking as I called my mum. I couldn’t even tell her in person because I was away at college for my final term before graduating. My mum answered the phone and I tried so hard to keep it together, but my voice was trembling. I don’t think I will ever forget the moment that I told my mother I had thyroid cancer. The words that no parent ever wants to hear come out of their child’s mouth. She was so strong for me, she told me that no matter what, I would get through this and that she would never leave my side. My parents came to visit me that day and they held me close as I cried. I could see the pain in their eyes; I could tell they were hurting for me. I got through this with the overwhelming love of my family.

Having cancer has made me realise how lucky I am. And I don’t mean that I’m lucky because I got cancer. I am lucky because I am alive. Not many people will understand this concept and how I can say that I am lucky that I went through this. As crazy as that sounds and as unlucky as I may feel at times and as sad as I can get on my hard days, I am alive. I have a purpose just like everyone else in this world. I have goals, and a meaning to life. Having cancer does not define me.

After countless doctors appointments and check ups, I then had to meet with different surgeons because the only way I could be cured from this was to have my whole thyroid removed. On December 15 2014, I had a thyroidectomy - a procedure to remove my entire thyroid gland. I had an amazing surgeon who I trusted and I knew that he would take good care of me. I remember crying so much once the surgery was over. I felt overwhelmed with emotions and relieved. I looked at my scar a couple of hours after surgery and I knew that I would wear my scar with pride. I overcame the hardest obstacle that I have ever had to face and I came out an even stronger person than I was before. Once my surgery was completed, I had to wait a couple of months to go through radioactive iodine treatment to destroy any remaining thyroid tissue in my neck. The final treatment was a success and in March of 2015 I got the news from the doctor that I was cancer free.

I take levothyroxine every day now. It took me some time to adjust to this medication and I’m still trying to get the correct dosage. I have days where I feel extremely fatigued and I feel like I have no energy at all. I am still dealing with anxiety and some depression that came from this experience. However, I have learned to cope. I have found myself through all of this. Hard times reveal your true strength. But most importantly, I have let this teach me about life instead of bringing me down. I have allowed myself to breathe and realise that I am alive, I am living and I have a bright future ahead of me.

My photo was taken one week after my surgery. I may not have a thyroid anymore, but I have my whole life ahead of me. This scar will represent a significant change in the course of my life. I am alive and I am thankful for every second of every day. Don’t ever give up because life is a beautiful thing and it is worth fighting for.
Feature

The thyroid and the cardiovascular system

The thyroid gland is responsible for regulating many vital bodily functions. A healthy thyroid produces just the right amount of thyroid hormone to help regulate the body’s metabolism and how much oxygen and energy your body uses, digestive function, muscle function and skin tone. The thyroid in fact has at least some effect on every organ in the body. Here we look at the effect on the cardiovascular system.

Impact on the heart

Any type of thyroid disease may have a direct impact on the heart. The heart reacts to any thyroid dysfunction: it will either speed up in the case of an overactive thyroid or slow down in the presence of an underactive thyroid. Without treatment thyroid disorders can worsen existing heart diseases or cause new ones.

How thyroid hormones affect your heart and blood vessels

The heart is a major target of thyroid hormones and will respond to any changes in thyroid hormone levels. When there is not enough thyroid hormone, neither the heart nor the blood vessels can function normally. The two main thyroid hormones produced are thyroxine (T4) and triiodothyronine (T3). Although the thyroid gland produces more T4 (80 percent) compared with T3, T3 is more active than T4 and is the thyroid hormone responsible for regulating heart rate, pulse, blood circulation, oxygen consumption and the way the heart pumps. Much of the T4 produced is actually converted into the more active T3 inside the cells of the body.

Too little thyroid hormone because of an underactive thyroid (hypothyroidism) can cause the heart to beat too slowly or irregularly, to flutter with missing or additional beats. As a result a type of arrhythmia called bradycardia may develop which leaves organs and tissues without enough oxygen and nutrients. An underactive thyroid can also over time, if left untreated, cause high blood pressure and an increase in cholesterol in the blood with the consequence of developing atherosclerosis (the buildup of fats, cholesterol and other substances in and on artery walls (plaques), which can restrict blood flow) - a risk for heart attack and stroke.

Too much thyroid hormone due to an overactive thyroid (hyperthyroidism) can cause chest pains and palpitations that do not show up during a heart check-up. An overactive thyroid can also cause an increase in blood pressure, the heart to beat faster and a form of arrhythmia (abnormal heart rhythm) called tachycardia may develop – a risk factor for heart attacks. Hyperthyroidism can also cause other arrhythmias such as atrial fibrillation.

Even mild hypothyroidism can have an effect on the heart

Subclinical (borderline) hypothyroidism affects four to 20% of the population and is more common in women than in men with the incidence increasing with age. Although the absolute risk of a problem is very low, recent studies have indicated that people with subclinical hypothyroidism occurring in middle age may be at a greater risk of developing heart problems. More studies are needed but a recent review of data from almost 50,000 people studying the risk of stroke in individuals with borderline (subclinical) hypothyroidism by Chaker et al (JCEM June 2015) identified that there was no clear association overall between subclinical hypothyroidism and stroke. However when studying only younger individuals (aged less than 50) those with subclinical hypothyroidism were over three times more likely to have a stroke. At present it is unclear whether treatment with levothyroxine will reduce the risk of stroke in these individuals. However a study in May 2012 by Razvi et al http://heartdisease.about.com/od/lesscommonheartproblems/a/thyroidheart.htm previously indicated that younger individuals with subclinical hypothyroidism who were treated with levothyroxine had reduced heart disease events than those who were not. These studies demonstrate an urgent need for clinical trials to assess the benefits of treating subclinical hypothyroidism on heart disease and stroke particularly in younger people.

Summary

It is important if you have a thyroid disorder (even if it is mild) to go for regular blood tests as recommended by your GP to ensure you are on the correct level of medication to reduce the chance of complications with your heart.

Symptoms of heart disease are much more likely to occur in people who have underlying heart disease from another cause so it is particularly important to be regularly monitored if you fall into this category.

Permanent changes in the heart are unusual in patients with a normal healthy heart, unless the thyroid disease is particularly severe and left untreated for long periods of time.

Sources:
http://thyroidweek.org/en/thyroid-and-heart
http://heartdisease.about.com/od/lesscommonheartproblems/a/thyroidheart.htm
http://www.thyroid.ca/e6a.php

Anon: I have an 18 year old daughter with an over-active thyroid. She is due to have radioactive treatment soon I would like to know if this will affect her fertility. The consultant did not really give me great confidence. Should we be concerned? Should we consider egg freezing? Any help would be greatly appreciated.

Our medical advisor replies: Radioactive iodine treatment has been used for 70 years and is not associated with a risk of reduced fertility later on. The advice is that women should not become pregnant for six months after the treatment in order to avoid risks to the fetus associated with the radiation. The equivalent gonadal dose (i.e. dose to the ovaries) one would get with a dose of 400 MBq of radioiodine is the same as having an abdominal CT scan. This is not an indication for egg freezing.

More information about radioiodine treatment for an over-active thyroid can be found at: www.btf-thyroid.org/index.php/thyroid/leaflets/radioactive-iodine-guide

JO asks: I was diagnosed 10 years ago with an under-active thyroid. Last year I was diagnosed with breast cancer and I have read some articles - some informative some frightening about a connection with taking levothyroxine. I wondered if any one could shed any light on this.

Our medical advisor replies: The link between thyroid disease and various forms of cancer including breast cancer have been debated for over 30 years. A number of studies have shown differing results. One study showed no link between an under-active thyroid and various types of cancers. A few others showed no or reduced risk in people with hypothyroidism (under-active thyroid). Similarly, some studies show that people on levothyroxine have a higher risk of breast cancer whereas many others have shown either no increased risk or even a reduced risk. The differences in these results from many studies is the reason why no one is clear regarding the exact link between the two. There are many differences between the various studies including the geography of where the patients were studied, the impact of other risk factors on both the thyroid and risk of cancer (for example, smokers have a higher risk of cancers as well as an over-active thyroid or older age is associated with increasing risk of both conditions) and how long patients were studied for. In addition, any link between two conditions doesn’t necessarily mean that they have a cause and effect relationship. It might be that a third factor may be having an effect on both conditions. So in summary there are reports of a link between thyroid disease and cancers but it is not confirmed definitively. This is the reason why specialists are currently unsure if this is a true link or not.

AN asks: I have an under-active thyroid and take 2.5ml of levothyroxine oral solution (100mcg per 5ml). After a scan last year a Gastro Liver consultant has requested I have a CT scan with contrast, which I’ve been told will have iodine in it. Will this be safe for me to have or not considering my thyroid? Five years ago my thyroid did go from under-active to over-active, however, it is now back to being under-active and has been for over five years.

Our medical advisor replies: Changes in thyroid function can be brought on by exposure to an iodine load. It would be useful to know if there was a suspected trigger that may have been implicated five years ago. That said, many patients with hypothyroidism tolerate imaging with contrast without incident and it may be reasonable to monitor the thyroid function more closely for 6-8 weeks after the scan is performed.
Graves’ Disease

Investigate the causes of

from the BTF

complication (GO) coordinated by

and

request for advice

results of thyroid

address the issue of harmonisation of thyroid testing:

ʻThe timely diagnosis and treatment of thyroid dysfunction is essential. This relies on adequate first-line laboratory testing of serum thyroid stimulating hormone (TSH) and free thyroxine (FT4). The laboratory and clinical community have long recognised the need to achieve comparability of measurement results between the methods available from different manufacturers.

The measurement of these two hormones in serum is challenging. They are both present in extremely low concentrations. The measurement of FT4 has to be performed in the presence of very much higher concentrations of thyroxine, which is bound to serum proteins. TSH exists in serum in several different forms, which means that it is not possible to define a single standard preparation, which is representative of all patients and conditions.

In response to this need, the IFCC has led a global project with input from academics, laboratory experts, proficiency testing organisers and the global companies that manufacture the TSH and FT4 methods. The results of this project have been published and advice is now being sought from doctors and from patients with thyroid dysfunction.

For FT4, the differences between methods of testing is substantial and all currently available FT4 methods give results that are lower than the new definitive reference procedure, with some methods yielding results less than 50% of the reference procedure. Re-calibration of the available FT4 tests is feasible so that all methods can be modified to give very similar results. However, this will require substantial method related changes in the lower and upper limits of current reference intervals for normal patients. The variability between the different TSH methods is significant but less dramatic than for FT4 - approximately 20%. It is possible to harmonise TSH methods to produce very similar results but this will lead to some modest changes to the upper limit of the reference interval for normal patients.

Doctors and patients are being invited to comment on the balance between the benefit of all methods giving very similar results and the risk that may arise from a change of reference intervals, including the impact on previous results for individual patients.

Any BTF member who would like to learn more about this important but complex study is invited to contact Dr Beastall at gbeastall@googlemail.com

International collaboration between scientists to investigate the causes of Graves’ Disease

In BT F News 89 (page12) we reported on INDIGO (Investigation of Novel biomarkers and Definition of the role of the microbiome In Graves’ Orbitopathy); a research project studying Graves’ Disease (GD) and its eye complication (GO) coordinated by Professor Marian Ludgate from Cardiff University School of Medicine. GD is an autoimmune condition in which the body’s immune system attacks the thyroid leading to hyperthyroidism; almost half of GD patients develop an eye complication that has considerable impact on general well-being and is not easy to treat.

What triggers the production of autoantibodies is unclear but it is thought to include genetic predisposition and environmental factors (stress, smoking). Several studies have shown that billions of different micro-organisms live in our gut influencing bowel activity and the immune system. The cooperation among research centres and scientists with different backgrounds aims to investigate whether micro-organisms present in our gut regulate our immune systems and could contribute to the process leading to GD and GO. Below, we highlight the work of two of these international researchers:

Hedda Luise Köhling (above right) from the University Hospital in Essen, Germany, will spend 12 months at a company called Cultech in South Wales that produces probiotics and food supplements. Hedda is training to specialise as a medical microbiologist and therefore used to lab work with bacteria. Danila Covelli (pictured left) from University of Milan, will join Hedda and they will spend six months together at Cultech. She will also spend six months at a company, Parco Tecnologico Padano (PTP), based in Lodi, Italy.

ʻI’m an endocrinologist and have been working in the Endocrine Unit at Ospedale Policlinico, Milan, since 2007. I’ve mainly worked at thyroid clinic and collaborated in clinical trials on GO patients’. During their time at Cultech Hedda and Danila have been involved in ‘test-tube’ experiments to re-create the intestinal ecosystem. Faecal samples from GD/GO patients and healthy controls have been used to stimulate cells and compare the cytokines (regulate the immune system) produced. The Cultech probiotic, Lab4, has been added to samples to identify any possible influence on cytokine production. Finally traditional microbiological analysis (the ‘bugs’ are grown on agar plates) and DNA extraction have been done on all faecal samples to identify the main bacteria living in the gut of GD/GO patients to compare with healthy subjects.

In the time Danila spends at PTP she will investigate whether GD/GO patients produce an immune response to gut micro-organisms or food derived antigens (antigens are the fragments recognised by antibodies). That will indicate whether microbial or food derived antigens are able to trigger thyroid disease or are associated with eye disease.’

Research

Is it desirable to harmonise the results of thyroid function tests? A request for advice from the BTF

Dr Graham Beastall, Past President of the International Federation of Clinical Chemistry and Laboratory Medicine (IFCC) explains details of a global study being undertaken to address the issue of harmonisation of thyroid testing:

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congenital anomalies; including congenital heart defects and other, mainly gastrointestinal and urinary defects. For the past six years I have been working with EUROCAT, an organisation that registers fetuses and babies with congenital anomalies throughout Europe, carrying out epidemiological research with a view to prevention; and laterally with the daughter organisation EUROmediCAT which is concerned with drug exposure in early pregnancy and its association with congenital anomalies.

I am thrilled to receive the BTF Evelyn Ashley Award and intend to use it in two ways: firstly I will use the money to pay for my time while I write a protocol for a piece of research that, when fully funded, I will carry out with the expert team here at Ulster University. We will use the EUROmediCAT database to estimate the association between thyroid disease in pregnancy and specific congenital anomalies, looking at hypothyroidism and hyperthyroidism separately. As maternal illness, both chronic illness and those that occur during pregnancy, are recorded in the database, we hope that we will be able to look at both treated and untreated disease.

Hypothyroidism during pregnancy has been associated with congenital anomalies, but many women suffer from both thyroid disease and diabetes that can also lead to congenital anomalies; and we hope to be able to begin to separate the effects of both in our analysis. There is some evidence that hyperthyroidism and/or the drugs used to treat it during pregnancy are associated with specific congenital anomalies. This is very difficult to research as hyperthyroidism is rare, as are specific congenital anomalies, and it takes a huge population to power such a study. The strength of EUROmediCAT is that we have such a population.

Our team is building expertise in linking data from national datasets and I will also be able to investigate what sources of data are available in the UK to examine thyroid disease in pregnancy. This will include thyroid disease, the medications used and any associated diabetes in pregnancy and birth outcomes such as miscarriage, prematurity and stillbirth. It may also be possible to link these to developmental outcomes for the live born children, but this has not been carried out so far.

Unfortunately, since not every pregnant woman gets her thyroid function tested, we will not be able to look at the effects of subclinical hypothyroidism, but we may be able to plan more research in the future. Like most other researchers, I am funded to carry out specific pieces of research. What the BTF Evelyn Ashley Award will allow me to do is to spend time planning, and most importantly, writing protocols for some of the research needed in this very significant area. The protocol, which the award will fund, is the first step, and I hope to be able to report that we have identified funding to actually carry out the research in the near future.

**BTF Research Award winner 2014 update**

**Management of hyperthyroidism during pregnancy; data from a large primary care cohort**

Dr Peter Taylor (left), Welsh Clinical Academic Trainee at Cardiff University and Dr Bijay Vaidya (right), Consultant in General Medicine, Diabetes and Endocrinology, Royal Devon and Exeter Hospital, explain how their research is progressing.

ʻWe were grateful to receive funds from the BTF to acquire access to a large primary care database. This will enable us to better understand and hopefully enhance the management of hyperthyroidism during pregnancy. In particular we will assess current UK management and identify deficiencies. Furthermore we will assess for the risk of adverse outcomes from hyperthyroidism and sub-optimal treatment including risk of miscarriage, congenital abnormalities and the need for medical intervention during labour such as for a caesarean section. At present we are still in the process of acquiring the data. However thanks to encouragement from the BTF we are also both currently analysing the Controlled Antenatal Thyroid Screening (CATS) study to explore the potential benefits of treating women with borderline hypothyroidism during pregnancy. Our analysis indicates that even borderline maternal hypothyroidism during pregnancy is associated with adverse outcomes. The treatment with levothyroxine of women with borderline hypothyroidism during pregnancy is also associated with favourable effects on both birth-weight and gestational age at delivery and may have some protective impact on reducing the risk of miscarriage.

**BTF Evelyn Ashley Award 2015**

Dr Breidge Boyle, Research Associate in Epidemiology at Ulster University, Institute of Nursing and Health Research is the winner of this year’s award of £1000. She explains here her role and how she will use the award:

I am a Registered Sick Children’s Nurse with more than thirty years’ experience. Much of my career was spent working in neonatal surgery where I have looked after babies with structural
BTF Evelyn Ashley Award Winner 2014 update

Greta Lyons. Endocrine Research Nurse at the Clinical Research Facility, Addenbrookes Hospital, Cambridge explains her work and how she used the £500 she was awarded:

I am an Endocrine Research Nurse working in a small multi-disciplinary team with aims of improving standards of care to patients (adults and children) with rare Resistance to Thyroid Hormone Alpha (RTHa) and Resistance to thyroid hormone Beta (RTHb). Our team is involved both nationally and internationally in the care of these patients. As part of this process I am required to have an in-depth knowledge of RTH. I visit patients in their homes and within other hospital environments in order to give families and patients flexibility, particularly if they are unable to travel great distances. This also allows equity of access to the service for all patients with RTH. My paediatric and health visiting qualifications complement the skills required for this. My ultimate goal is to have an adaptable, collaborative working relationship with families and their local teams.

Over the last year the endocrine nurses’ module has been in the process of being validated and will run at a new institution in the future. In order to move forward with my knowledge I attended two different symposia, using part of my award that has relevance to our patients with RTHa and RTHb. I plan to use the remainder of the money, from the award, to go towards the paediatric endocrine module when this is established.

I attended a fantastic symposium on Attention Deficit Hyperactivity Disorder in Liverpool, which was run by the ADHD foundation itself. I deliberately targeted this meeting, as it was a very practical session for teachers, support workers, volunteers, and medical professionals. I was able to hear how children, their families and adults are affected by this condition and learn various methods to support them both at home and in the classroom.

The second area that I was keen to focus on was dyspraxia. I was able to attend an equally fantastic course run by the Dyspraxia Foundation in Manchester. This again was a course to inform parents, teachers, support staff, volunteers and health professionals in the best strategies in supporting families and adults with this condition.

Whilst both courses allowed me to glean a wealth of information and help for my patient leaflet, I was struck by the absolute determination and commitment of all attendees to provide the best care they were able to for their families.

Going forward I am now in the process of constructing a useful leaflet for our patients. I will also be developing a leaflet to help parents explain what thyroid hormone does to their child and how the condition of RTH can affect the individual. I believe this is a way of helping to improve communication, care and support for this patient group.

Due to the publicity of the award I have been invited to speak at British Thyroid Foundation patient support group meetings. I have not only enjoyed the audience/patient participation but it has given me a platform to inform people of our continued work here with our patients.

I am extremely grateful for the support from the British Thyroid Foundation and the Evelyn Ashley Smith award to have given me the opportunity to develop my knowledge in order for me to influence and strengthen the nursing and clinical care for our patients.

BTF Doris Godfrey Research Award 2016

The BTF offers an annual award to support a one-year research project into thyroid function or thyroid disorders. This year’s award is up to £20,000 and has been funded by a legacy from Doris Godfrey, a children’s nurse who suffered from hypothyroidism. The impact of thyroid disease on herself and particularly her mother motivated her to arrange a legacy of £48,000 for the BTF. (see page 1 BTF News 88).

The deadline is 31 January 2016.

Full details and an application form are on the BTF website www.btf-thyroid.org/index.php/awards/research-awards
Leave a legacy to the BTF

Help to make a real difference by remembering BTF in your Will. Any gift, large or small, makes a real difference. Legacy donations allow us to continue providing life-changing support to people with thyroid disorders.

If you do decide to remember BTF in your Will, your gift will mean that BTF will still be here for people who need our support in years to come. By leaving a legacy you can take advantage of the reduced rate of inheritance tax of 36% (previously 40%) that came into effect from April 2012 for estates leaving a legacy to charity. Call 01423 709707 or email legacies@btf-thyroid.org for an information pack.

Shop online and raise money!

easyfundraising.org.uk

Have you heard about easyfundraising yet? It’s the easiest way to help raise money for the BTF! If you already shop online with retailers such as Amazon, M&S, Argos, John Lewis, Comet, Vodafone, eBay, Boden and Play.com then we need you to sign up for free to raise money while you shop!

So how does it work?

You shop directly with the retailer as you would normally, but if you sign up to http://www.easyfundraising.org.uk/cause/btf for free and use the links on the easyfundraising site to take you to the retailer, then a percentage of whatever you spend comes directly to us at no extra cost to yourself.

How much can you raise?

Spend £100 with M&S online or Amazon and you raise £2.50 for us. £100 with WH Smith puts £2.00 in our pocket and so on. There are over 2,000 retailers on their site, and some of the donations can be as much as 15% of your purchase.

Save money too!

easyfundraising is FREE to use plus you’ll get access to hundreds of exclusive discounts and voucher codes, so not only will you be helping us, you’ll be saving money yourself.

Buy a teddy and support the BTF

Buy one of these adorable teddies for £6.99 + £2.50 postage per order and all the profit will go towards the BTF. Go to the BTF website to order online or by cheque by downloading and sending with the order form on the website.

Unity Lottery

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

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

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

Birmingham
Next meeting: Saturday 7 November 2015 11am to 1pm.
Location: Yardley Baptist Church, Rowlands Road, South Yardley, B26 1AT, off the A45 Coventry Road. Free parking available.
Programme: Guest Speaker - Dr Carla Moran, winner of this year’s BTF Research Award will be speaking about her current thyroid research.

Leeds (Wharfedale)
Next meeting: See the BTF website for more details
Contact: Caroline on 0113 288 6393 or email: efie1237@btinternet.com

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

Donation: Suggested min donation £3.
Contact: Mary on 01223 290263 or email: btf.cambridge@gmail.com

Cambridge
Next meeting: A research themed meeting is planned for Spring 2016. Details will be posted here or contact Mary (details below)
Location: Friends’ Meeting House, Jesus Lane, Cambridge CB5 8BA.

Donation: Suggested min donation £3.
Contact: Denise on 07984 145343 or email: denisesims@btf-thyroid.org

Leeds (Wharfedale)
Next meeting: See the BTF website for more details
Contact: Caroline on 0113 288 6393 or email: efie1237@btinternet.com

London
Next meeting: 28 November 2015 10am to 1pm.
Location: Crown Court Church, Russell Street, Covent Garden, London WC2B 5EZ http://www.crowncourtchurch.org.uk/where-to-find-us/
Programme: Support and Social with guest speaker - Nicki Williams (Happy Hormones) - http://happyhormonesforlife.com

Milton Keynes
Next meeting: See BTF website for details
Location: The Pavilion, Open University, Milton Keynes, MK7 6AA.
Donation: £2 voluntary donation.
Contact: Wilma Tel: 01908 330290 or see www.thyroidmk.co.uk or find us on Facebook.

Yeovil
Next meeting: See BTF website for details
Contact: Janet on 01935 827794 or email: janet.neale4@btinternet.com

Are you interested in bringing people together to start a BTF support group in your area?
In particular we would welcome new groups anywhere in the North East, the North West, the South Coast, the Bath/Bristol area and Wales. Training and support from BTF HQ is available. Email c.mcmullan@btf-thyroid.org

The BTF local groups have had a busy few months:

The Cambridge group held a very informative panel meeting in the summer of patients and clinicians including Judith Taylor, expert patient and former Chair of the BTF, Dr Jassim Ali, Cambridge GP and Greta Lyons, Thyroid Research Nurse at Addenbrooke’s Hospital and BTF Evelyn Ashley Nurse Award winner 2014 (see page 13).

The Birmingham group held a meeting in September with guest speaker Dr Kristien Boelaert, Reader in Endocrinology, Consultant Endocrinologist University of Birmingham who talked about hyperthyroidism and Graves’ Disease. The presentation covered a wide range of topics including the different types of overactive thyroid diseases, their differences and other autoimmune disorders. After the presentation Dr Boelaert stayed to answer questions and have a chat with members of the audience.

A large and appreciative audience enjoyed listening to Dr Peter Hammond (left), Consultant Endocrinologist Harrogate District Hospital when he spoke at the Leeds (Wharfedale) group in September on a wide range of thyroid issues, followed by a lively question and answer session.

Did you know
Pandas have hypothyroidism too!

Scientists at the Chinese Academy of Sciences and Aberdeen University have worked out why pandas are so relaxed and how they survive on a diet of bamboo alone – it’s their thyroid! The researchers studied three wild pandas at Foping Nature Reserve in Shaanxi province and five captive pandas at the Beijing Zoo. They found that they use a fraction of the amount of energy of other similar sized animals and have extremely low levels of thyroid hormones due to a mutation in a gene involved in thyroid hormone synthesis. They found that their thyroid levels are in fact similar to those of a black bear in hibernation. Source: www.dailymail.co.uk/sciencetech/article-3154929/C123rf.com
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>Coordinator</th>
<th>Phone Number</th>
<th>Email</th>
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<tbody>
<tr>
<td>Birmingham</td>
<td>Janet</td>
<td>0121 6287435</td>
<td><a href="mailto:janetdmp@googlemail.com">janetdmp@googlemail.com</a></td>
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<tr>
<td>Cambridge</td>
<td>Mary</td>
<td>01223 290263</td>
<td><a href="mailto:btf.cambridge@gmail.com">btf.cambridge@gmail.com</a></td>
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<tr>
<td>Edinburgh</td>
<td>Margaret</td>
<td>0131 6647223</td>
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<td>Leeds (Wharfedale)</td>
<td>Caroline</td>
<td>01132 886393</td>
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<tr>
<td>London</td>
<td>Denise</td>
<td>07984 145343</td>
<td><a href="mailto:denisesims@btf-thyroid.org">denisesims@btf-thyroid.org</a></td>
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<tr>
<td>Milton Keynes</td>
<td>Wilma</td>
<td>01908 330290</td>
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<td>Yeovil</td>
<td>Janet</td>
<td>01935 827794</td>
<td><a href="mailto:janet.neale4@btinternet.com">janet.neale4@btinternet.com</a></td>
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BTF TELEPHONE SUPPORT CONTACTS

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<tr>
<td>Cambridge</td>
<td>Mary</td>
<td>07939 23613</td>
<td><a href="mailto:btf.cambridge@gmail.com">btf.cambridge@gmail.com</a></td>
</tr>
<tr>
<td>Jackie</td>
<td>PC</td>
<td>01344 621836</td>
<td></td>
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<tr>
<td>Gay</td>
<td>(G,T,S)</td>
<td>020 8735 9966</td>
<td></td>
</tr>
<tr>
<td>Karen</td>
<td>(U)</td>
<td>01628 529212</td>
<td></td>
</tr>
<tr>
<td>Wilma</td>
<td>(U)</td>
<td>01592 754688</td>
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<tr>
<td>Angela</td>
<td>(U)</td>
<td>01943 873427</td>
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<tr>
<td>Maria</td>
<td>(U)</td>
<td>020 87934360</td>
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</tr>
<tr>
<td>Ursula</td>
<td>(U)</td>
<td>07720 659849</td>
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</tr>
<tr>
<td>Colin</td>
<td>(O,R,I,U)</td>
<td>07973 861225</td>
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<tr>
<td>Olwen</td>
<td>(O,R,I,U)</td>
<td>01536 513748</td>
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<tr>
<td>Jane</td>
<td>(G,R,I,TED,G,U)</td>
<td>01737 352536</td>
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<tr>
<td>Peter</td>
<td>(TED,GR)</td>
<td>01200 429145</td>
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<tr>
<td>Helen</td>
<td>(O,T,S,TED)</td>
<td>01858 410094</td>
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</tr>
<tr>
<td>Penny</td>
<td>(Ch)</td>
<td>01225 421348</td>
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KEY

- **6 - 8pm weekdays**
- **2 to 5pm Monday, Tuesday and Thursday**
- **After 6pm weekdays and anytime weekends**
- **10am to 2pm weekdays**
- **2 to 8pm Tuesdays and Wednesdays**
- **up to 8pm**

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](http://www.amend.org.uk)
- **Hypopara UK** Helpline: 01342 291397 [www.hypopara.org.uk](http://www.hypopara.org.uk)
- **Thyroid Cancer Support Group Wales** Tel: 08450 092737 [www.thyroidsupportwales.co.uk](http://www.thyroidsupportwales.co.uk)
- **British Thyroid Cancer Support Group Ireland** [www.thyroidcancersupport.ie](http://www.thyroidcancersupport.ie)
- **British Thyroid Cancer Trust** Tel: 01207 545469 [www.butterfly.org.uk](http://www.butterfly.org.uk)
- **Cancer52** [www.cancer52.org.uk](http://www.cancer52.org.uk)
- **Thyroid Eye Disease Charitable Trust** Tel: 0844 8008133 [www.tedct.org.uk](http://www.tedct.org.uk)
- **British Thyroid Association** [www.british-thyroid-association.org](http://www.british-thyroid-association.org)
- **Thyroid Cancer Support Group Wales** [www.thyroidcancersupportwales.co.uk](http://www.thyroidcancersupportwales.co.uk)

CURRENT MEMBERSHIP RATES

<table>
<thead>
<tr>
<th>Membership Type</th>
<th>UK</th>
<th>Overseas</th>
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<tr>
<td><strong>Annual</strong></td>
<td><strong>Cheque</strong></td>
<td><strong>Standing Order</strong></td>
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<tr>
<td>Members living in the UK</td>
<td>£20 per year</td>
<td>£17 per year</td>
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<tr>
<td>Members living overseas</td>
<td>£25 Europe</td>
<td>£35 Outside Europe</td>
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</table>

Concession: unwaged and children under 18. Please help us by ensuring that you pay the correct subscription.

Order your BTF Christmas cards

We have a great collection of contemporary and traditional Christmas cards that we are selling to raise funds for the BTF. We would be very grateful for your support. You can order your Christmas cards cards now by filling in the flyer enclosed with this newsletter or by visiting the BTF website: [www.btf-thyroid.org](http://www.btf-thyroid.org).