Janis Hickey awarded MBE in New Year Honours list

Janis launched the BTF in March 1992, with the support of a small group of thyroid specialists. Her many years of hard work, energy and dedication have now been recognised with an MBE in the New Year Honours list 2019.

Thyroid disorders affect one in 20 of the UK population but prior to the existence of the BTF there was little focus on the needs of these people. The thousands of patients who were affected by thyroid disease had no access to basic information about their diagnosis. They had limited understanding of the way thyroid disorders could impact their lives. Patients were usually given no guidance about how to manage their health and Janis set out to change this.

Janis worked with some of the UK’s leading medical experts to produce reliable information and encourage the patient voice to be heard. Patients are now more informed and supported with valuable patient literature, covering all areas of thyroid disease including congenital hypothyroidism, thyroid eye disease and thyroid cancer.

Janis told us: ‘Although it was with some trepidation I opened a letter in November from the Cabinet Office marked ‘Personal’ and ‘Urgent’, once I had I was thrilled to read that ‘...The Prime Minister is asking me to inform you … she is recommending that Her Majesty the Queen may be graciously pleased to approve that you be appointed a Member of the Order of the British Empire (MBE) in the New Year 2019 Honours list’. It took a while to absorb, and of course I couldn’t tell anyone until the list was published on 28 December!’

‘I feel very honoured to have received this award for founding the BTF and ‘for services to people with thyroid disease’, and would like to thank everyone who supported the nomination. I’ve received some lovely messages of congratulations from colleagues and members – thank you! I’m very grateful to the many people who’ve supported the BTF since its beginnings in 1991 to make it the successful organisation it is today.’

Congratulations Janis and thank you for your service to the thyroid community!

How can the BTF help you? Members’ Survey 2019

Listening to patients’ needs and campaigning for improvements in their care has always been a priority for the BTF. The last membership survey was in 2015 and the results helped our trustees identify membership priorities and concerns and set the strategic direction that would guide the charity to a successful and sustainable future.

We would now like to gather an up to date picture of your views so please take a few minutes to complete the 2019 Survey that is enclosed with this newsletter. You can also complete the survey online through SurveyMonkey https://www.surveymonkey.co.uk/r/NHNDQ9H. We will also be seeking the views of patients from across the UK and the medical professionals we work with. The completed forms should be returned by 29 March 2019. Once we have analysed the feedback we will publish the results in the BTF News and on the BTF website.

If you would like a large print version of the survey please contact the office. Tel: 01423 810093 or email info@btf-thyroid.org
Welcome to...
Our new telephone contact Jenny Allen. Jenny is happy to take calls from any women struggling with Postpartum Thyroiditis. We would like to thank Jenny for giving her time to support the BTF.

Farewell to...
Angela Court-Johnston who has left the BTF to take up a new challenge. Angela was with us from March to November 2018 and worked tirelessly in her role as fundraiser. We would like to thank Angela and wish her all the best for the future!

BTF information now translated
Thanks to Ania Marchwiak who kindly offered her translation expertise to make the BTF Hair Loss and Thyroid Disorders and the Diet and Thyroid Factsheet accessible to Polish patients.
We are also grateful to three members of the British Thyroid Foundation, Dr Justyna Witzc, Dr Ishrat Khan and Dr Hussam Abusahmin who helped with the translations of the updated BTF leaflets. They are now available to read online in Polish, Arabic and Urdu.

Funding News
Avizors Community Funding Awards

We were delighted to be chosen from about 3,500 small charities to get through to the final of the Avizors Community Funding Awards. This fund awards 500 grants to small charities who believe they are making a positive difference in local communities throughout the UK. A big thank you to all the BTF members who voted for us, we couldn’t have done it without you!

Quality of life questionnaire
Joe Straw, BTF Trustee is completing his studies at Sheffield Hallam University this year and is asking for patient input for his chosen dissertation topic.
Joe writes ‘I will be researching how physical activity levels affect quality of life whilst we live with hypothyroidism. This is the first study of its kind into hypothyroidism and physical activity.
To conduct the study, a combined questionnaire will be available to fill out using both the ThyPRO questionnaire for thyroid disease quality of life and the IPAQ (International Physical Activity Questionnaire) which measures physical activity levels. The link to the questionnaire will be available on the BTF website and social media groups. ‘Living with thyroid disease can be tough, even for people who appear to have normal blood levels, and nobody really knows if physical activity can help. To get the most reliable results for my study we need as many people as possible with hypothyroidism to complete the questionnaire and this may pave the way for further research.’

For more details about this study please email: joe.straw.1992@gmail.com

News from BTF

Big Lottery Fund
We have received funding from the Big Lottery Fund to support the upcoming BTF Children’s Conference which will be held on Saturday 8 June in Birmingham. It will be our third children’s conference and we are hoping it will be as successful as the past events. We will be working with paediatric and other specialists from Birmingham Children’s Hospital and the University of Birmingham, who will give talks and run workshops about various thyroid disorders and the way they may affect children. Patient speakers will also be there to give their own insight into how they’ve managed as they’ve grown up with thyroid disease.
Thanks to the support from the Big Lottery Fund we are able to offer places at the event free of charge. To find out more about the event and to book a place please email children@btf-thyroid.org
BTF Projects Update

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

Children

The BTF has been invited to support a study that will help researchers understand more about the causes and impact of congenital hypothyroidism. Dr Pia Hardelid, Lecturer in Epidemiology at UCL Great Ormond Street Institute of Child Health is leading the study, Congenital thyroid Dyshormonogenesis: establishing Risk factors and Outcomes using population-based data linkage Methods (CD-ROM).

Dr Hardelid writes: Since the introduction of newborn congenital hypothyroidism (CH) screening 40 years ago, there has been an increase in the proportion of babies born with CH, particularly a type called thyroid dyshormonogenesis. We do not know why dyshormonogenesis is becoming more common, or how much it affects health, development and learning as children grow up. In this study, we will examine reasons for the increase in dyshormonogenesis. We will also investigate health and education profiles for children with dyshormonogenesis, and show how these compare to those of children with other forms of CH, and unaffected children. We will use data that are routinely collected in the NHS and state schools in North London and surrounding counties. We will link these datasets to create health and education histories for children with CH, and unaffected children. Our results will inform parents, children and clinicians about the health and education consequences of congenital thyroid dyshormonogenesis, and public health professionals about if and how dyshormonogenesis can be prevented.

Another study supported by the BTF is the British Paediatric Surveillance study of congenital hypothyroidism which looked at the incidence of CH in the UK and other important issues surrounding this condition. The BTF is leading the study, Congenital thyroid Hypothyroidism outcomes using population-based data linkage Methods (CD-ROM) which will examine health and education histories for children with CH, and unaffected children.

Iodine

The UK Iodine group (UKI) is gearing up to organise educational activities for health professionals when the Royal College of Gynaecologists and Obstetricians’ Greentop Guidelines on Pregnancy are published at the end of this year. The Guidelines contain a section on pregnancy and iodine, and emphasise the important role that iodine plays in brain development in a child’s early years. Specifically, we need to underline the important message both to health professionals and to women with a normal functioning thyroid (i.e. who have not been diagnosed with a thyroid disorder) that unborn babies and newborns need a good supply of iodine and that means that pregnant or breastfeeding women should ensure they have enough iodine in their diet.

As January was Veganuary month we took the opportunity to emphasise the need for adequate iodine in the diet, and responded to an article published in the Daily Express on 3 January 2019 about vegan diets and vitamin/mineral requirements. We pointed out that currently there is evidence of iodine deficiency in UK pregnant women (vegan and non-vegan), that good sources of iodine are white fish, milk, dairy products, and eggs, and that women who do not eat these foods need an alternative source of iodine. We also stated that it is better to take a supplement (the Vegan Society supplies a suitable one) rather than seaweed such as kelp, as this can contain very high amounts of iodine, which could be harmful.

UKI is looking into pregnancy supplements in order to provide recommendations. It is also working with British Salt who is negotiating supplying iodised salt to UK supermarkets.

Liothyronine is not being followed by CCGs, was published in November 2018. The authors of the report are now calling for NHS England to exercise its formal powers to intervene on behalf of patients and ensure that those who need liothyronine have access to it through the NHS, regardless of which CCG they come under. Follow this link to read the Patient Dossier. https://bit.ly/2QCN41w

Professor Krishna Chatterjee, President of the British Thyroid Association states ‘The current uncertainty, with liothyronine-treated individuals either being denied ongoing prescriptions or needing to source the treatment themselves at their own cost, seems very much against patients’ interests.’

Dr Peter Taylor of the Thyroid Research Group at Cardiff University has analysed NHS open prescribing data and identified widespread variation in liothyronine prescribing throughout England. His findings have been published in the Lancet: Endocrinology and Diabetes https://bit.ly/2SVUkH6

Cost and number of T3 prescriptions per 100 T4 prescriptions’

Hypothyroidism

The Goldilocks principle, ie not too much or too little, but just right, is important when prescribing thyroid hormone replacement, especially in the elderly, or women of reproductive age. In a recent article GPs and endocrinologists presented the results of their multi-practice audit which evaluated the monitoring of patients on thyroid hormone replacement in primary care. ‘Thyroid hormone replacement: applying the Goldilocks principle’ Prescriber Dec 18 https://bit.ly/2H66Pit

As reported in BTF News 99 (p4) thyroid patient groups have collaborated to produce a report that gives clear evidence about the harm being done as the result of the widespread failure of local NHS bodies to consistently follow national guidelines on the prescribing of liothyronine.

The report Liothyronine – Case Details with Clear Evidence that NHS England Guidance on Prescription of Liothyronine is not being followed by CCGs, was published in November 2018. The authors of the report are now calling for NHS England to exercise its formal powers to intervene on behalf of patients and ensure that those who need liothyronine have clear access to it through the NHS, regardless of which CCG they come under. Follow this link to read the Patient Dossier. https://bit.ly/2QCN41w

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A big thank you to Joe Straw!

Joe Straw completed the final challenge of his Five@25, the Mam Tor Marathon on 13 October 2018.

Joe Straw on his final challenge.

Joe says: I completed the run from Dore, on the edge of Sheffield, to Mam Tor, a hill in the Peak District. I started off strongly and despite it being a very windy day I managed to get to the finish without any difficulties. It was a great way to finish off the last of my five fundraising events. I would like to say a huge thanks to everyone who has supported me. It wouldn’t have been achievable without all the support I received throughout!

The BTF would like to say a massive thank you to Joe for all his fundraising efforts throughout 2018 and for raising £1032 for the BTF.

Poetry collection published

When Larissa Reid began suffering from the strange beginnings of hypothyroidism last year, she challenged herself to write a poem every day for a month. Larissa told us: Starting on 1 February, and taking writer Robert Macfarlane’s ‘words of the day’ on Twitter as inspiration, I began to write poems, many fuelled by my love and need for the natural world, particularly at times of crisis.

The result is my first small collection of poetry. I have decided to donate all profits from the sale of this book to the BTF in support of the valuable work they do across the UK. If you would like a copy of the book, priced £5.99, it is available online at twistedcolon.blog.

Team ‘Can’t stop running for the hills’

Claire and Liz Millward, Jo House, Masha Shaverneva, Michaela Hills and Susan Crummeay took part in a number of challenges throughout 2018.

The team raised funds for the BTF and Support Dogs in memory of their special friend, Melissa Hills. Between them they took part in a triathlon, a sprint triathlon, the Spartan Super (obstacle race), the Spartan Sprint, the Spartan Beast (a 12-mile obstacle race), a climb up Ben Nevis, and the National Three Peaks Challenge. They even found the time to hold a bake sale!

Yorkshire Marathon

Two brave runners took part in the Yorkshire Marathon on 14 October 2018 so thank you to both of them for their commitment and dedication.

Mark Eggington told us: At the tender age of fifty I’ve only gone and done it! My official time was 3:59:30, which was under my four hours target so I don’t care how close it was, I was under! The weather was not very hospitable for spectators, volunteers or runners (wet and cold) however the support was fantastic all the way round. I wouldn’t have achieved that time without it.

I am really pleased with not only raising nearly £620 (excluding Gift Aid!) but also raising awareness of a common, but not very well known, condition.

John Whittington also took part and says: I don’t class myself a runner, well probably not until today anyway. Being an asthmatic with an underactive thyroid and high blood pressure, running never really appealed to me.

A couple of months ago, my dentist announced that he was running the Yorkshire Marathon to raise money for a cancer hospice, maybe it was just a knee jerk reaction, but running a marathon to raise money for a charity seemed that logical next goal, after running in my local ‘parkrun’ since 2016.

The thyroid is not something that often gets thought about and many people are not sure what it does and the dark places it can take you to, when it’s not working correctly.

I completed the marathon in a time of 4:11:16, far exceeding any mental goal. Although it rained the whole run and I got a huge black blister on the underside of my foot, I was happy! John raised £571 for the BTF.
If you are interested in taking part in any of these events please ring 01423 810092 or email fundraising@btf-thyroid.org for a place.

A marathon a day!

Zara took part in her school ‘marathon’, to run a mile a day during her break and lunchtimes, to raise funds for the BTF. Although she was quite unwell she would run whenever she felt well enough and managed to run six miles.

Zara raised a fantastic £185 for BTF.

Bournemouth Marathon
Jamie Hadwin completed the Bournemouth Marathon on 7 October 2018. Jamie says: I finished the Bournemouth Marathon. It was tough, but I’m so glad I did it as raising money for the BTF means a lot to me. Jamie raised £175 for the BTF.

BTF Charity Places for 2019

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<tr>
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<tr>
<td>Saucony Half Marathon Cambridge</td>
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<td>Run For All Half Marathon Sheffield</td>
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<td>Simplyhealth Great Manchester Half Marathon</td>
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<td>Simplyhealth Great North Swim One Mile – Windermere</td>
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<td>ASICS London 10k</td>
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<td>Simplyhealth Great North Run Half Marathon – Newcastle</td>
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<td>Simplyhealth Great Birmingham Half Marathon</td>
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<td>Simplyhealth Great South Run Ten Miles – Portsmouth</td>
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<td>Jane Tomlinson Yorkshire Marathon York</td>
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<td>Simplyhealth Great Bristol Half Marathon</td>
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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.
Cambridge Ophthalmological Symposium: the thyroid and the eye

Each year scientists and clinicians from all over the world meet to debate an eye related theme. In September 2018 the topic was ‘The Thyroid and the Eye’. The co-chair, Marian Ludgate, Professor Emirata, School of Medicine, Cardiff kindly provided this report.

I walked across the Bridge of Sighs in search of...breakfast! For this was not Venice but St John’s College Cambridge where the Cambridge Ophthalmological Society (COS) dedicated two days to discussing the latest advances and research in Thyroid Eye Disease (TED) for their annual international symposium.

I was privileged to be one of the co-chairs, along with Professor Tim Sullivan, an oculoplastic surgeon from Brisbane, Australia. Together with the organisers, Dr Rachna Murthy and Professor Keith Martin from COS, we compiled an impressive programme covering all aspects of TED, from events happening in a single orbital cell to improved surgical approaches.

The highlight of the meeting was a report from Dr Terry Smith (Michigan, USA), who described a recent trial in which TED patients treated with a drug, initially designed for cancer, had a significant improvement in proptosis (the bulging eyes characteristic of TED). His collaborator Dr Ray Douglas (Beverly Hills, USA) explained the science behind the drug’s action, which targets a receptor for a natural growth factor on the surface of orbital cells. The growth-factor receptor was also the focus of Professor Suzanne Neumann’s (Bethesda, USA) work, and in particular how it ‘talks’ to the thyroid receptor, which strangely is also found at the surface of orbital cells. In the discussions which followed it became clear that the drug trial needs to be repeated to confirm the results, and also compared with the steroid therapy currently used to manage TED, before being extended to all suitable patients.

Talks from Dr Maryse Bailly (London) and Lei Zhang (Cardiff) described their efforts to understand fibrosis, the process leading to muscle stiffness and problems with eye movement and to unravel what happens inside an orbital cell in TED to identify new treatments.

Professor Mario Salvi (Milan, Italy) and Professor Joanne Jones (Cambridge) and Dr Diego Strianese (Naples, Italy) described the effects of two drugs which target the immune system. The first removes B cells (cells that make antibodies and autoantibodies) and several trials have shown that some TED patients benefit. The other drug removes both B and T cells (cells that attack cancer and viruses, and regulate B cells) and greatly improves another autoimmune condition, multiple sclerosis (MS). However, as the B and T cells return, some patients develop Graves’ disease (GD) and TED. Whilst not being of any help in treating thyroid problems, the treated MS patients provide a wonderful opportunity to study what happens as GD and TED evolve.

Apart from this human model of GD/TED, it was most heartening to hear that major progress has been made with a thyroid-receptor induced mouse model to help increase understanding of the disease. Professor Anya Eckstein (Essen, Germany) described the work of her group, including state-of-the-art imaging techniques equivalent to those used in patients. In collaboration with Dr Giulia Masetti (Cardiff) they found that the micro-organisms present in the mouse gut could influence the GD/TED and that disease severity was greatly decreased by antibiotic treatment from a very early age. However much more work is needed before this can be applied to people.

The study of the microbiome attempts to understand how our gut bacteria can affect the immune system was presented by Professor Julian Marchesi (Cardiff) who described preliminary results of microbiome studies in GD patients with and without TED. Major differences were observed and further analysis is underway to identify the ‘bad bugs’. Such an approach, together with the 21st century methods described by Dr Filippo Biscarini (Milan, Italy) could help identify which patients would benefit from existing and novel treatments in the future.

Day two was dedicated to more clinical aspects including how surgery has improved with time (Dr James Garrity, Rochester, USA); the recognition of different TED sub-types (Dr Jimmy Uddin, London); technological advances in imaging (Dr Tilak Das, Cambridge) and how TED differs in Asian people (Dr Seah Lay Leng, Singapore) and children (Prof Sullivan). Dr Peter Dolman (Vancouver, Canada) covered the very important topic of assessing quality of life in those with TED; discussions identified the vital role played by patient support groups such as the BTF and TEDct and highlighted the need for professional counselling in some instances.

The final session was dedicated to the specific surgical procedures applied in sight-threatening TED (Dr Mike Kazim, New York, USA); to correct squint and double vision (Dr Mike Clarke, Newcastle) and to improve the appearance once TED has finally subsided (Dr Bob Goldberg, San Diego, USA).

In my career of over thirty years I have attended many conferences dedicated to increasing understanding and improving management of TED. Considerable strides have been made in enhancing patient outcomes and I am optimistic that ongoing studies will lead to further advances. Such progress follows meetings such as this one and I greatly appreciate COS for choosing TED as its topic.

BTF/Fight For Sight Small Grant Award

Dr Maryse Bailly and Dr I-Hui Yang, University College London have sent the following update about their research project ‘A novel pathway regulating adipogenesis in Thyroid Eye Disease: characterization of spontaneous lipogenesis and validation of novel therapeutic targets’ which is funded by a BTF/Fight for Sight Small Grant.

Thyroid Eye Disease (TED) is a severe and potentially blinding disease of the tissues in
Claire was diagnosed with Graves’ disease two years ago. She got in touch with BTF to share her experiences

I had been unwell for roughly seven years and to be honest I’d got used to feeling like that. Sadly because of other health problems my thyroid issues were never addressed. When I changed surgery and attended my first appointment for a basic health check I sat down and shook hands with the nurse as we started to go through my health and medications. She looked at me for some time and asked whether I always sweated and shook like that and I said well yes, I have done for probably about seven years.

The nurse got me to lay on the bed and hooked me up to a heart monitor. She then left the room and returned with another nurse and a doctor. I was asked if I had any chest pain or weakness. I couldn’t understand what they were so worried about but my heart was beating at 202 bpm (or beats per minute, the average is between 60-100 bpm) They removed the stickers and replaced the machine because how could that be right with no chest pain?! I was sent straight to hospital and I was put on medication to slow my heart rate down which it did to about 168 bpm. I’d noticed my eyes were looking really puffy and no amount of cold compress or eye masks made a difference. I just tried to get on with life but was still feeling pretty terrible.

I was discharged but sometime after that my legs just gave way and I couldn’t get up. I thought it best to see my doctor again who said she thought I had Graves’ disease and so would send me to see a specialist as a matter of urgency. Within a few days I was saw a thyroid specialist who requested lots of blood tests. At the following appointment I was told my thyroid was so toxic it had started to attack my large muscle groups and that’s why my legs were so weak. I began on a high dose of tablets and was referred to an eye specialist to start weekly intravenous steroids. Everything seemed to be moving so fast. I’d also started to lose my hair rather rapidly.

My thyroid antibodies just kept rising and one morning I woke feeling really unwell. My legs gave way again and I couldn’t get up. I was admitted to hospital and taken to a ward where I was prepared for plasma dialysis. The surgeons couldn’t operate on me because my thyroid hormone levels were too high and the risk was too great. I started the treatment every morning for nine days and began to experience an unusual feeling of being well. I really liked it and couldn’t wait to get this thyroid out and start living again!

I had my bloods checked every day to see if the treatment was working and on the ninth day my levels started to drop and the treatment finally began to work. The surgery (total thyroidectomy) was still high risk though and I was told I would be in intensive care and would more than likely be in a coma for a while.

Fortunately, the surgery was successful and I spent only five hours in intensive care before they realised I was well enough to return to a normal ward. I still couldn’t walk properly and the physiotherapists warned me that it may be two years before I would be walking again.

Now that to me was a challenge so I began trying to walk with my wheelchair. I was doing this all day and though it was exhausting I began to feel my legs again and they didn’t feel as heavy. I was told that the antibodies may hang around for about a year then they would disappear. At my follow up appointment my surgeon told me they had also found a little cancer (micropapillary thyroid cancer) so he would see me every year for five years to check everything was ok.

That year I also had radiation treatment on my eyes. Although my eyes are still swollen they are better than they were and I’m due to see my eye surgeon to see if surgery would be an option to remove the fat from my eyelids, which the thyroid eye disease causes. Sadly my antibodies are still floating about and have caused an issue with my feet (thyroid dermopathy).

My advice would be that Graves’ disease can certainly be a battle but never give up! Keep you sense of humour and you will beat it. I can honestly say the operation itself was the easy part, it was pain free and very fast to heal. If I talk too long my voice tends to go hoarse but that’s it. So to all you thyroid warriors out there, huge hugs and the best of luck!

Comment from our medical advisor, Dr Salman Ravzi:
Plasmapheresis or plasma exchange is a therapeutic option that is occasionally used in severe hyperthyroidism where a quick reduction in thyroid hormones is required prior to more definitive treatment being administered. It is usually performed in intensive care settings and leads to a temporary reduction or even normalisation of thyroid hormone levels, which means that procedures such as thyroid surgery can be done in a less risky manner.

It is a highly effective blood purification procedure used to treat a variety of disorders, such as autoimmune diseases or severe sepsis. It is a safe and useful process whereby blood is separated via centrifugation or filtration into plasma and cells. The cells are then returned to the patient, replacing the plasma with either donor plasma, fresh frozen plasma, albumin, or a similar colloidal solution.

the orbit behind the eyeball, commonly affecting patients with thyroid problems. In over 90% of cases, expansion of orbital tissues and fat are responsible for most of the detrimental disease manifestations, and thus an understanding of how this happens is crucial to the development of suitable treatments. TED is poorly understood and treatment options are limited, often leaving patients with permanent disfigurement and double vision. Most of the swelling in TED results from an expansion of the fat behind the eyeball, as local cells, called fibroblasts, turn into fat cells. However, why and how those cells change in TED is still unclear, preventing significant developments in prevention and treatment.

To better understand how fibroblasts turn into fat in TED, our team has grown patient cells in soft gels made of collagen, an essential component of the tissues in the orbit. Under such conditions, fibroblasts from TED patients spontaneously produce fat, visualised as small intracellular lipid vesicles, mirroring what happens in the disease. Our early work indicated that fibroblasts in TED can make fat from sugars (a process termed de novo lipogenesis) and/or absorb fat directly from the circulation. However, they turned out to be only marginally better at doing so than normal orbital fibroblasts, which didn’t explain the large difference in the ability to make lipid vesicles we see in the lab.

We have now identified a protein that may be behind the TED fibroblasts ability to turn into fat cells. This protein is present on the lipid vesicles, potentially stabilising them. It is expressed at higher levels in TED fibroblasts compared to non-diseased ones, and its further increased when the cells are placed in the pseudo-physiological collagen environment compared to plastic dishes.

We are currently in the process of recruiting some patient and control biopsies to test whether it is also present at higher levels in diseased tissue compared to normal orbital fat. If confirmed, we believe we may have found a key molecular component of the disease, and a potential new marker for disease progression.
Flaxseed tablets

Our member asks: I have an underactive thyroid and I am on levothyroxine. A friend has suggested I start taking flaxseed tablets for dry eyes and I was wondering whether I can take flaxseed tablets if I am on levothyroxine.

Our medical advisor replies: We have no real evidence to suggest that you should not take flaxseed tablets but as with all food supplements and thyroid medication it should be used sparingly. The evidence tends to lean towards not using it but there are also papers recommending it and we appreciate how confusing this is when the evidence is not robust in favour one way or the other.

I would rather suggest you try and find out the root cause of your dry eye problem initially as this can be caused by a variety of factors that may not be solved by flaxseed tablets. It might be worthwhile asking your GP to refer you to an ophthalmologist if this is a chronic problem. Sometimes the tear flow may be at fault or your eye is too exposed, these are just examples but this may require a full eye examination.

Additive free thyroxine

Our member asks: I need to take additive free levothyroxine which unfortunately only has a month’s shelf life. I’ve been getting this medicine from the pharmacy for 15 years. The pharmacy told me they now cannot dispense it to me because of a national shortage of levothyroxine. My hospital pharmacy has told me the same. Do you know anything about a national shortage?

Our medical advisor replies: We have not heard of any shortage of levothyroxine so I contacted your pharmacy today. Their pharmacist told me that there was no national shortage but as you have a special prescription it may be that there is a temporary hold up on the preservative free capsule for some reason. This could be due to a number of things such as the company being relicensed or low stock. Her advice was to go back to your pharmacy and ask them to contact the company to find out what the delay is and how long it is likely to be. It may be possible to get supplies from another branch? She implied that there were usually ways around this problem even if means your GP prescribing another brand for a short period.

E-cigarettes

Our member asks: I was diagnosed with Graves’ disease in 2016. I was given the ‘block and replace’ method of treatment (to take anti thyroid drugs to stop your thyroid gland producing thyroid hormone and start taking levothyroxine to replace the thyroid hormone your body would normally produce) and since May 2018 I have been off all medication. My thyroid levels have remained consistent.

New neighbours moved into the flat below me at the end of October 2018. I started exhibiting skin rashes as well as a tightness in my chest. It was only recently that I discovered the lady was smoking e-cigarettes. Our flats are not well sealed and to an extent, we share the same air space.

I have read that many people are allergic to propylene glycol, which is a chemical found in e-cigarettes. Is this putting a strain on my immune system and like cigarettes, are e-cigarettes just as harmful for people with thyroid disease?

Our medical advisor replies: It does sound as though you may be having an allergic reaction. Your symptoms sound very similar to those reported by others who have suffered from allergies attributed to e-cigarettes. The propylene glycol and glycerol by themselves are thought to be harmless but combined with the heat they can decompose and produce harmful chemicals and toxins such as formaldehyde.

As to whether you are more at risk because of your thyroid problems it is difficult to say. There has not been much research done on e-cigarettes per se although the risks of smoking and passive smoking with Graves’ disease are well known. Some e-cigarettes contain nicotine but these would be inhaled by the person using the e-cigarette and not yourself. However, if you are experiencing allergic type symptoms I would suggest you consult your GP just to check that nothing else is going on. If this looks like an allergic reaction then you may need to have a chat with your neighbour, which may be a little more difficult.

Thyroid cancer treatment: how long should you suppress the TSH?

Our member asks: At the age of 10 in 1996, I was diagnosed with metastatic papillary carcinoma of the thyroid. I had been presenting a goitre and several lumps to the sides of my neck from the age of about six. Doctors initially didn’t take my mother’s concerns about these seriously and so it took those few years to get a biopsy and final diagnosis. By then, the cancer had progressed to stage 2, and several metastases were showing on my lungs on a CT scan.

Later in 1996 I had a total thyroidectomy and following the surgery I made a full recovery after four rounds of radioactive iodine therapy. Fortunately, I do not need to take calcium supplements thanks to the excellent surgeon, who managed to preserve most of my parathyroid glands.

I was formally discharged from treatment in September 2006 after my last outpatients check up appointment and I currently take 125mcg of levothyroxine (L-T4) daily. Other than this, I am fit and well, and have not been under the care of any doctors other than GPs for this.

I recently moved to Essex and at registration my GP wrote to the oncologist who discharged me in 2006 with regard to appropriate dosage of L-T4 in my situation. The oncologist advised that my current dosage of 125mcg was fine, with the following note: ‘I would be happy for Laura’s TSH to be kept below normal range but not fully suppressed less than 0.1 at this point in time.’

I was delighted to become pregnant in September 2018, and have been since under the care of a maternity thyroid specialist at my local hospital in order to monitor my TSH and T4 levels throughout pregnancy.

I am now 4.5 months pregnant. I last spoke to the specialist on the phone this week. He seemed satisfied that my latest TSH and T4 were appropriate, and said I wouldn’t need further TSH / T4 monitoring until six weeks after the birth. I asked if he considered my TSH / T4 to be at ‘normal range’ (ie: NOT suppressed) and he said yes.
I then raised a query about the requirement of TSH suppression due to the thyroid cancer treatment, and he changed his mind and said I should up my dose temporarily to 150mcg per day. I have a follow up appointment with him in six weeks to look at TSH / T4 and discuss the situation.

I am interested in other opinions with regard to an appropriate daily dose of L-T4 for someone in my situation, so I can be better prepared for this next meeting with the specialist. I have seen research which suggests that long term suppression of TSH with L-T4 can cause other problems such as osteoporosis / heart problems, without any evidence that this treatment actually prevents recurrence of cancer. Being female, 33 years old, and having to take L-T4 for the rest of my life, I am understandably concerned about the risk of these and other problems developing in later life. To me, it seems to make more sense to stay at 125mcg daily and monitor my thyroglobulin levels annually to detect any potential recurrence of cancer, rather than overmedicate 'just in case'. I would love to know if you have any thoughts on this, and if there are any BTF members who have gone through a similar situation at a relatively young age.

Our medical advisor replies: I am sorry to hear that you have been affected by metastatic thyroid cancer at a young age. I am delighted that you are now in complete remission and pregnant 22 years on from the original diagnosis.

We used to suppress serum TSH indefinitely for patients with papillary thyroid cancer, especially if they presented at a relatively advanced stage, and clinical practice guidelines in 1996 and 2006 would have endorsed the management you have received. As you correctly point out long-term suppression of TSH may be associated with adverse health outcomes relating to the cardiovascular system and to osteoporosis.

Current guidelines indicate that following completion of treatment a dynamic stratification of risk needs to be undertaken to assess the response to treatment. Since you are now in remission with no evidence of recurrent or residual disease you would be considered to fall into the excellent response category and the recommended TSH target would be the lower half of the normal reference range (0.4-2.0 mU/l). Indeed monitoring would be by checking unstimulated thyroglobulin concentrations.

During pregnancy and especially in the first twenty weeks the recommendation is to keep TSH below 2.0 mU/L and often this requires an increase in the dose of levothyroxine by 30-50%. Whilst practice is varied in the UK and across the world many practitioners will check thyroid function tests on a four weekly basis until 20 weeks and once per trimester thereafter, assuming thyroid tests are stable. The TSH targets of someone who has previously had differentiated thyroid cancer and who is pregnant are the same as those for the non-pregnant population. We usually advise that women continue the dose of levothyroxine they are taking at the end of pregnancy for two weeks following delivery of the baby and then revert to the pre-pregnancy dose. Indeed a further test of thyroid function at six weeks post-partum is appropriate. I feel that the TSH target for you during the remainder of and following pregnancy should be 0.4-2.0 mU/l.

Hair loss and thyroid disorders

Hair loss is a distressing condition which can have many causes. Some thyroid disorders can cause hair loss and it is one of the topics that we are most often asked about.

Dr Petros Perros, Consultant Endocrinologist, Newcastle, Professor John Hunter, Emeritus Professor of Dermatology, University of Edinburgh and Professor Mark Strachan, Consultant in Diabetes and Endocrinology, Edinburgh produced this article to help people understand more about the different causes of hair loss and suggest some ways of managing the condition. The article is also available to read on the BTF website.

Abnormal hormones are often blamed for loss of scalp hair though, perhaps surprisingly, they are responsible for just a small minority of instances of this distressing symptom. Many different conditions can lead to hair loss; some hair loss is part of normal life. Women after childbirth and at the time of the menopause can lose hair and almost every man will lose some hair by the time of reaching adulthood. Elderly males and females will develop baldness of various degrees, which is largely determined by genetic factors.

Human scalp hair does not grow continuously. Every hair follicle (the unit of hair production) undergoes phases of growth, during which hair lengthens, followed by a period of rest (the telogen phase). During telogen, the hair is shed and replaced by a new hair. In some animals this process is synchronised; that is why dogs lose a lot of hair at the same time or ‘moult’. Human hair growth is not coordinated in the same way, so at any one time different hair follicles are at different stages of their growth cycle. So, it is normal to have some ongoing continuous hair loss, which usually is balanced by new hair growth.

One of the commonest causes of hair loss is called ‘telogen effluvium’. This can be triggered by any severe illness, for instance pneumonia or a major operation. The stress of the illness causes all hair follicles to go into their resting phase and hair growth temporarily ceases. Because the human hair cycle is long (several months), the hair loss may not become apparent for several months, by which time the person will have recovered from their illness. Such hair loss also coincides with new hair beginning to regrow and therefore the hair loss is transient.

continued on page 10
Hair loss and thyroid disease

Severe and prolonged hypothyroidism and hyperthyroidism can cause loss of hair. The loss is diffuse and involves the entire scalp rather than discrete areas. The hair appears uniformly sparse. Regrowth is usual with successful treatment of the thyroid disorder, though it will take several months and may be incomplete. It is unusual for mild (e.g. subclinical) hypothyroidism or hyperthyroidism, or short-lived thyroid problems to cause hair loss.

Some forms of hypothyroidism and hyperthyroidism come on abruptly and are diagnosed early, while others may have been present for months or years before diagnosis. Hair loss due to thyroid disease becomes apparent several months after the onset of thyroid disease. This is due to the long hair cycle. In such cases, paradoxically the hair loss may follow the treatment for the thyroid and the thyroid medication may be erroneously blamed, leading to withdrawal of treatment, which in turn may worsen the hair loss.

Hair loss and anti-thyroid treatment

Anti-thyroid drugs (carbimazole and propylthiouracil) can, in rare cases, cause diffuse hair loss. It may be very difficult to tell whether the hair loss is due to the effects of the previous overactivity of the thyroid or the anti-thyroid drugs. In all probability the anti-thyroid drugs are not the cause and it is unusual to have to seek alternative treatment for hyperthyroidism. Radioiodine does not cause hair loss.

Hair loss associated with autoimmune thyroid disease

Most people with hypo- or hyper-thyroidism have autoimmune thyroid disease. If a person has one autoimmune disease they are more likely than others to develop some other autoimmune condition. Alopecia areata is an autoimmune condition that causes hair loss that occurs in people with autoimmune thyroid disease more often than expected by chance. Unlike the types of diffuse hair loss described above, alopecia areata causes discrete, often circular, areas of hair loss. In most cases this is transient and does not progress, but unfortunately it can cause significant baldness. There are other rare autoimmune conditions that can cause hair loss through scarring (e.g. lupus erythematosus), which are associated with autoimmune thyroid diseases. Polycystic ovarian syndrome is also associated with autoimmune thyroid disease and may manifest as diffuse hair loss; other features are irregular periods, obesity and acne.

Investigations for hair loss

If you are experiencing hair loss and it is enough to cause concern, you should seek advice from your GP. It is unusual for thyroid disease to cause hair loss without other symptoms of an over- or underactive thyroid. Your doctor will decide if it is appropriate for you to have additional tests to exclude other causes of diffuse hair loss such as iron deficiency. There are also rarer causes of hair loss, which your GP may feel are worth excluding. Sometimes referral to a skin specialist is required in order to make an accurate diagnosis.

What can I do?

Most cases of scalp and eyebrow hair loss caused by thyroid disorders are temporary, but it may take several months for the medication to stimulate your hair to regrow. Try to be patient as regrowth can be unpredictable, and be aware that new hair may differ in texture and colour.

It helps to know you’re not alone, and that it is usual to feel a psychological impact of hair loss. If you’ve lost your hair, even temporarily, life will be easier if you can accept what’s happened, focus on all your positive qualities and, if necessary, enhance your altered appearance.

Talk to your loved one, friends and family. Join a support group that shares stories and information such as Alopecia UK www.alopecia.org.uk. It is also well worth reading the NHS coping tips for hair loss. https://bit.ly/2FiPvF1

Don’t be taken in by miracle cures, and be aware that the problem may not be associated with your thyroid. Get advice from your doctor or specialist. Some people feel better disguising or covering up hair loss with wigs, hair extensions, scarves or make-up. You may be eligible for help through the NHS. https://bit.ly/2FiOvOE

Listen to tips from qualified and experienced hairdressers. Avoid using hair straighteners or braiding as this puts traction on already frail hair. Use wide toothed brushes or combs. Take care in washing, treating and grooming your hair.

Be wary of home use products, and use recommended professional products for dye, highlights and conditioning. Although caffeine-containing shampoos are popular they are not useful.

Certain ‘hair supplements’ should be avoided as they may contain iodine or interfere with levothyroxine absorption. Avoid products high in iodine (such as kelp) and ‘thyroid support products’ as they can be dangerous and cause either underactivity of the thyroid (hypothyroidism) or in some cases overactivity (hyperthyroidism). Only take iodine supplements if recommended by your GP or hospital consultant. Preferably have a varied and healthy diet, with calcium-rich foods and/or supplements taken four hours apart from your levothyroxine dose. Discuss this with your pharmacist if in any doubt.

Sister Margaret Morris

One of our members, Brenda Glencross, asked if the BTF would say a special thank you to Sister Margaret Morris who has retired from her role at the Freeman Hospital, Newcastle. Brenda says: Margaret is a very professional nurse, hardworking, who listens to what patients have to say and has a good sense of humour.

Margaret, who has worked with BTF on the TEAMeD project, told us: What I have come to realise in my time as a specialist nurse is that it is not always just the medication we prescribe. It is just as important to listen to the patient, help them to understand their condition and empower them to manage their condition. I would really like any younger nurse to realise this because I think that is the real art of nursing.

The BTF wishes Margaret a very happy retirement!
**Edinburgh**

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. Members of the BTF Edinburgh Group attended the Scottish Parliament on 4 December 2018 to watch the debate on ‘Effective thyroid and adrenal testing – diagnosis and treatment’. After the debate they had a chance to meet some of the politicians who took part. To watch the debate go to https://bbc.in/2UckfvH or read about the debate on the Scottish Parliament website. On 23 January 2019 four members of the BTF Edinburgh Support Group were invited to attend a consultation meeting at the Edinburgh Medical School. The meeting was led by Dr David Kluth, Director of Undergraduate Teaching. The aim of the consultation was to involve lay people to participate in the development of the Medical Curriculum for first- and second-year students. Some of the subjects covered were: Challenges of the Future, What Patients Need, How Teaching should be Informed by New Scientific Developments and How Students should be Assessed.

**Future meetings:**
- 26 Feb 2019 – Ellen Spinner (registered Nutritional Therapist) will speak about ‘Nutritional strategy for regaining full health after thyroid disease’.
- 30 April 2019 – Maggie Carson, Lecturer in Nursing Studies at Edinburgh University, will present her research findings on the use of T3 by thyroid patients.

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

**Contact:** Margaret Tel: 0131 664 7223 or email: m2mccgregor@aol.com

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### Bristol

The group meets on the second Wednesday of each month from 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

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### Cambridge

**Next Meeting:** Saturday 16 March, 10am-12.30pm

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

**Speaker:** Dr David Halsall, Consultant Clinical Scientist & Director of Specialist Endocrine Testing Laboratory, Cambridge University Hospitals Trust. His talk will be on Thyroid Function Tests (blood tests).

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

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### Milton Keynes

**Next Meeting:** 2 March 2019

Group work – thanks to feedback from our members we recognised that people want to talk, discuss, exchange ideas acquire more information about their thyroid condition. For this reason, this event will be about you! You can tell your story, listen to others and learn from each other’s experiences.

**Future meeting:** 8 June 2019

**Speaker:** Dr Vasco Fernandes MBBS, DCH, MRCGP, FFFHM. (retired Milton Keynes NHS Consultant Physician)

His talk will include:

- A general introduction to thyroid conditions.
- Issues related to thyroid conditions.
- Dealing with situations that may arise.
- Latest information and research in the headlines.

**Future Meeting:** 12 October 2019.

This will be an opportunity to meet the CEOs from the BTF 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.
**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) | Milton Keynes – Wilma (U) | 01908 563289 |
| Cambridge – Mary (O,RI,U) butterlyecho@hotmail.com | Edinburgh – Margaret (PC) | 0131 6647223 |

**BTF TELEPHONE SUPPORT CONTACTS**

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

A M E N D

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

H ypopara U K

Helpline: 0134 2 316315 www.hypopara.org.uk

Thyroid C ancer Support G roup W ales

Tel: 0845 0 300709 www.thyroidsupportwales.co.uk

I rish C ancer Society

www.cancer.ie email info@irishcancer.ie

B utterfly Thyroid C ancer Trust

Tel: 01207 54 54 69 www.butterfly.org.uk

C ancer52

www.cancer52.org.uk

Thyroid Eye D isease C haritable Trust

Tel:074 69 921782 www.tedct.org.uk

B ritish Thyroid A ssociation

www.british-thyroid-association.org

B ritish A ssociation of Endocrine and Thyroid Surgeons

www.baets.org.uk

**THE B RITISH THYROID F OUNDATION**

Suite 12, One Sceptre House, Hornbeam Square North, Hornbeam Park, Harrogate HG2 8PB

Tel: 01423 810093 www.btf-thyroid.org Office enquiry line open: Mon to Fri 9.30am–4pm.

**Key**

**Ch** Thyroid disorders in Children

**PT** Postpartum Thyroiditis

**PC** Papillary Cancer of the thyroid

**CS** Thyroid Cancer Surgery

**RAI** Radioactive Iodine (I-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: 0134 2 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

**CURRENT MEMBERSHIP RATES**

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<th>By standing order</th>
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<td>£25 Europe</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.

**PLACES ARE STILL AVAILABLE FOR THE FOLLOWING EVENTS**

- Run For All Half Marathon Sheffield
- Simplyhealth Great Manchester Half Marathon
- Simplyhealth Great North Swim Windermere
- ASICS London 10K
- Simplyhealth Great North Run Newcastle
- Simplyhealth Great Birmingham Half Marathon
- Simplyhealth Great South Run Portsmouth (10 miles)
- Jane Tomlinson Yorkshire Marathon York
- Simplyhealth Great Bristol Half Marathon