BTA booklet awarded Highly Commended at BMA Patient Information Awards

Providing reliable and accessible information for patients is at the heart of all the BTF does. It was therefore a privilege to attend an awards ceremony in central London on 25 September and to discover that the latest edition of the BTF’s booklet Thyroid Cancer: for Patients by Patients had been Highly Commended by the judging panel of the British Medical Association (BMA) Patient Information Awards.

The BMA Patient Information Award was established in 1997 to encourage the production, dissemination and evaluation of patient information materials which are evidence-based and well designed. Such information should also support patients as active participants in decisions about their care. The awards are organised by the BMA Library and demonstrate the BMA’s commitment to the provision of consumer health information.

Thyroid Cancer: for Patients by Patients (third revised edition) has been written to help patients facing a diagnosis of thyroid cancer and those who are caring for them. It takes the reader through the steps they may face along the way: from diagnosis, treatment, follow up care, and life after cancer. Many thyroid cancer patients helped to write the booklet, through the review and update process, and by contributing to the ‘patient experiences’ at the end of each chapter. The resource aims to help patients understand their diagnosis, to answer many of the questions they may have, and to help them be more confident about the treatment and recovery they face.

The judging panel commented ‘This is an excellent resource and is likely to be of considerable value to patients facing a thyroid cancer diagnosis.’

Cheryl McMullan and Julia Priestley represented the BTF alongside Peter Esslemont who was one of the patient reviewers. Peter said ‘As a thyroid cancer patient myself I really enjoyed helping produce the BTF’s revised thyroid cancer booklet. Receiving a ‘Highly Commended’ accolade was an honour and a great compliment to everyone who was involved.’

We are very grateful to all those who have helped in the production of the book since its first edition in 2006 and also to Sanofi Genzyme who kindly made a grant towards the cost. Special thanks go to the late Carole Ingham, former BTF trustee and volunteer who was involved in the development of the first edition and was an invaluable member of the BTF thyroid cancer group for many years.

The booklet is available free of charge to patients and hospitals and as a free download on the BTF website. https://bit.ly/2tqoB11
Welcome to…

Dr Anna Mitchell

Originally from the South East of England, moved to the North East to study medicine in 1999. She trained in diabetes, endocrinology and general medicine and is now a Clinical Academic Intermediate Fellow at Newcastle University and Honorary Consultant Endocrinologist at the Newcastle upon Tyne NHS Hospitals Foundation Trust. She is particularly interested in autoimmune endocrine diseases, including Graves’ disease and thyroid eye disease, and her research focuses on why people develop these conditions. She is a member of the European Group on Graves’ Orbitopathy (EUGOGO) and the Thyroid Eye Disease Amsterdam Declaration Implementation Group (TEA-Med).

Volunteer training day

On 30 June 2018, BTF invited all its fantastic volunteers to attend a training day in London. Many of the BTF telephone contacts were able to attend along with Wilma Beckett who coordinates the BTF’s longest running group in Milton Keynes. We were delighted that Lorna Pankethman, BTF new medical letter co-ordinator was also able to attend.

The day began with a Q&A session by Dr Mark Vanderpump. He answered many of the frequently asked queries that are received from callers. Mark also updated the volunteers on recent developments in medication and thyroid treatments.

After lunch, Julia Priestley gave a presentation on the BTF projects and updates. Cheryl McMullan then went through some useful information, including new guidelines that would hopefully support them in their role.

The BTF received some positive feedback from the volunteers. Describing what aspect of the training they found particularly useful, one volunteer stated: ‘Sessions were very different and all useful. I was very glad to have Mark Vanderpump’s session to begin. He was very informative.’

Should you wish to become a BTF volunteer, we would be delighted to hear from you. For information on volunteer opportunities please ring 01423 810093 or email info@btf-thyroid.org

Well Done!

Well done to Helen Dawson, BTF Accounts Assistant and a Sister in the Clinical Assessment team at Harrogate Hospital, on winning the ‘Making a Difference Award’.

Helen was nominated by a patient in recognition of making a difference. The patient said how Helen’s positivity and happiness was uplifting, making the patient feel comfortable and really making a bad day so much better!

Well done Helen you thoroughly deserve it!

BTF Christmas cards

Our range of Christmas cards 2018 is now on sale. We hope you like this year’s designs, and that there is a choice for everyone. You can also buy the BTF wristbands, trolley key rings and teddy bears, which would all make great stocking fillers! All you need to do is complete the enclosed order form and send it to the address stated on the form, or telephone your order to: 01227 811612. The order form can also be downloaded from the BTF website: http://www.btf-thyroid.org/

Personalised Christmas cards are also available in any of our designs. Please call 01227 811612 for details.

All proceeds from the sale of our cards go towards supporting the work of the BTF and also will help raise awareness of thyroid disorders.

News from BTF
Out and About

Thyroid Cancer Symposium
Surgeons, endocrinologists and oncologists came together at the Royal College of Physicians in London this summer to discuss and learn about ‘New Developments and Controversies in the Management of Thyroid Cancer’. It was a new and well-attended opportunity to raise the profile of the BTF and the work done for thyroid cancer patients.

Cambridge Ophthalmological Symposium
The BTF were invited to have a stand at this international scientific meeting, the focus of which was ‘The Thyroid and the Eye’. Janis Hickey and Lorna Pankethman represented the BTF. A summary of the important and ground-breaking research presented during the symposium will be included in BTF News 100.

European Thyroid Association
The 41st Annual Meeting of the ETA took place at the Sage building, on the south bank of the River Tyne, Newcastle upon Tyne in September 2018. Cheryl and Julia from BTF attended the meeting. It gave them the opportunity to meet other thyroid patient support groups from around the world. The stand also attracted numerous thyroid specialists from overseas.

We had a spectacular view from the BTF stand, which looked over the River Tyne and the Tyne Bridge.

Developing links with the Harrogate community
While BTF is a national charity and is supported by the local groups we have been developing links with local businesses in Harrogate, as a way of raising the profile of our work locally.

On 4 October head office held BTF’s first networking event and invited people from the local area to visit the office.

Angela Court-Johnston, BTF Fundraiser told us ‘I was very surprised about how many companies share the business park here. I realised that in a very small community, quite a number of people were affected, either directly or indirectly, by thyroid disorders. It is always a pleasure to meet people first hand, showcase our range of patient support literature and demonstrate that there is help available.

We are now hopeful that conversations with individuals will lead to opportunities to engage with local businesses who would like to fundraise for or work with the BTF in other ways.’

British Association of Endocrine and Thyroid Surgeons (BAETS)
The annual meeting of BAETS took place on 11-12 October in Glasgow. Julia Priestley represented the BTF at the event to which surgeons and other specialist doctors from all over the UK came together to share the latest developments in treatments and surgical management of thyroid and endocrine patients.

New stage play to explore impact of thyroid cancer
Writer/performer Lorna Nickson Brown will be performing her stage play, BUTTERFLIES at the end of November. The play is produced by Birmingham Repertory Theatre in partnership with the Butterfly Thyroid Cancer Trust and explores the impact a thyroid cancer diagnosis can have on the mental health of people who have experienced a diagnosis. BUTTERFLIES is a journey of self-discovery; into finding one’s voice, overcoming our fear of losing everything we love and asking, what is it to live a meaningful life?

BUTTERFLIES will be performed at Birmingham Repertory Theatre on 23 and 24 November with a possible tour to regional venues in 2019. Bookings can be made via https://www.birmingham-rep.co.uk/

The researchers said: ‘The painting suggests a yellowish discolouration of the skin, which is known to occur in hypothyroidism. The black veil that hangs below what appears to be a large forehead indicates a receding hairline, with hair that appears to be thinned. A complete lack of eyebrows or other hair throughout the pale skin further supports this diagnosis and cascading hair down the side appears coarse in character. Curiously, a close look at the neck does insinuate the possible presence of a diffuse enlargement such as a goitre.’

Iodine deficiency was a common problem among Italians during the Renaissance which was caused by a lack of dairy products, seafood, meat, bread and eggs. As a result goitres were common and depicted in painting and sculptures of the time.

Endoscopic technique allows removal of thyroid and parathyroid with no visible scar
A new procedure that allows surgeons to access and remove the thyroid and parathyroid glands through small incisions on the inside of the mouth has produced successful results and no visible scarring on the neck. Dr. Raymond Grogan, associate professor in the Michael E. DeBakey Department of Surgery at Baylor College of Medicine, Texas described how the procedure works and outlines its benefits.

Traditionally, surgeons remove the thyroid and parathyroid glands through a small horizontal incision in the centre of the neck. The scar size depends on the size of the gland, with the average size being 4-6cm long. The new surgery applies the same laparoscopic or endoscopic techniques that are used to remove the gall bladder, appendix or colon.

Published data reveals that the complication rates for this procedure are comparable to the traditional approach.
The BTF is focused on several key thyroid-related areas with the aim of raising awareness, assisting with research and improving the patient’s experience. Current projects are a hypothesis care strategy, pregnancy and thyroid disorders, iodine deficiency and subsequent thyroid problems, children with thyroid conditions, thyroid cancer and thyroid eye disease.

BTF Projects Update

The BTF is focused on several key thyroid-related areas with the aim of raising awareness, assisting with research and improving the patient’s experience. Current projects are a hypothesis care strategy, pregnancy and thyroid disorders, iodine deficiency and subsequent thyroid problems, children with thyroid conditions, thyroid cancer and thyroid eye disease.

BTF information leaflets

The BTF information guides have long been a valuable resource both for patients and the medical profession. Every two to three years the fourteen leaflets are reviewed by the BTF Members’ Panel and our medical advisors, and revised and updated as appropriate. The latest versions of the leaflets, which incorporate the BTF Membership Form, have been prepared over the last few months and will soon be available in print and on line. The two-page Quick Guide version has also been updated and will also be available on line.

We are grateful to the Society for Endocrinology who provided a Patient Support Grant to support the costs of new leaflets. Thank you also to the patients and medical advisors who helped with the process.

Copies of the leaflets are available free of charge to patients and hospitals who request them. The guides are also available to read and download from the BTF website. https://bit.ly/1scqveL Translations of all leaflets into Urdu, Arabic and Polish are also being prepared.

Hypothyroidism

On 19 July the BTF was invited, along with other thyroid patient groups and Prof Krishna Chatterjee, President of the British Thyroid Association (BTA), to take part in a meeting at the House of Lords. The discussion followed debates in both Houses of Parliament about the high cost of liothyronine and the distressing impact this was having on patients who are prescribed it.

Lord Hunt of Kings Heath, Shadow Spokesman for Health and Social Care who chaired the meeting, requested that the groups produce a dossier that collates clinical evidence to show that the NHS guidelines are not being followed. It is hoped that as a result of this document ministers will put pressure on NHS England to provide clarification on how guidance on liothyronine treatment will operate.

The patient groups worked on the dossier over the summer and the document will be sent to Government Health Minister Lord O’Shaughnessy in October.

Hyperthyroidism

Researchers in Birmingham are planning a new study into weight gain following treatment for hyperthyroidism. Jonathan Hazlehurst, Academic Clinical Lecturer in Endocrinology, University of Birmingham writes ‘Patients with hyperthyroidism lose weight prior to their diagnosis. Our data show that patients gain weight when they are treated and that this weight gain may be in excess of what they had lost before starting treatment. We are planning to study a large national database to determine which treatment (tablet, surgery or radioactive iodine) is associated with more weight gain and if the risk of developing conditions like diabetes is different between these treatments.’

We recently held a discussion evening in Birmingham that was advertised locally as well as to BTF members. The issue of weight management following treatment for thyroid disease was a significant concern to those that attended and common themes came out including: delayed initial diagnosis; the lack of a discussion about weight at diagnosis and that there were no options to support weight management across treatment. We are currently applying for funding for this research and if we are successful the project will begin next year.’

In August the British Medical Association featured an online article to help improve GPs’ understanding of patients presenting with a new diagnosis of hyperthyroidism. The article described typical cases and provided a helpful guide to assessment, diagnosis and treatment options. It stressed the need to give an explanation of the disorder and reassurance, and covered information to convey to patients including the likely outcome of treatment, possible adverse symptoms, and patient resources – the BTF and TEDct were highlighted. GPs were also advised to conduct appropriate blood tests in order to identify patients with suspected Graves’ disease – an autoimmune cause of hyperthyroidism – and prompted them to alert patients diagnosed with Graves’ disease to the symptoms of thyroid eye disease so that early treatment could be offered. The ‘Ten Minute Consultation’ was written by Dr Gabriella Bathgate, a specialist trainee in general practice, and her colleagues at the Royal Free London NHS Trust, and contributors included Dr Anh Tran, a GP with a special interest in endocrinology and Janis Hickey, BTF.

BMJ 2018; 362 doi: https://doi.org/10.1136/bmj.k2880 (Published 24 August 2018)

In BTF News 98 Apitope announced positive results from the first clinical trial for its novel therapeutic vaccine for the selective treatment of the autoimmune disorder Graves’ disease. This treatment targets the immunological basis of Graves’ disease and demonstrates potential to be the first innovative treatment in more than 60 years. Results from the study were presented at the September 2018 European Thyroid Association, meeting by Dr Simon Pearce, Professor of Endocrinology, Newcastle University, and Chief Investigator for the trial and it is planned to publish the clinical trial data for the community to see in the near future. More information will be provided in BTF News 100 so watch this space.

Apitope have also recently published scientific research data in a leading endocrinology medical journal. The paper describes how the vaccine was discovered. More information is available by following this link https://apitope.com/apitope-announces-publication-of-graves-disease-data-in-international-peer-reviewed-journal-endocrinology/.

Janis Hickey, BTF, who attended the European Thyroid Association meeting commented, ‘It’s encouraging that there were such positive results in the Phase I trial, and exciting to think that a potential cure for Graves’ disease is on the horizon.’

Pregnancy

The new BTF Thyroid and Pregnancy Alert Card is now available. Please see the feature on Thyroid and Pregnancy in BTF News 98. If you would like to order one please email pregnancy@btf-thyroid.org. See also the new BTF Pregnancy and Thyroid Disorders - Guidance for Patients https://bit.ly/2u2yNTp
We are very grateful to Dr Anh Tran, a GP in Surrey with a special interest in promoting thyroid health and medical IT, who has developed an electronic ‘thyroid and pregnancy’ protocol for use in primary care. The protocol gives reminders to GPs to offer written advice on thyroid disease and pregnancy to women of reproductive age with or at risk of thyroid disease. The protocol is being trialed in three primary care practices, with the aim of helping to improve management and monitoring of thyroid patients in pregnancy.

One doctor who has been using the protocol has sent the following feedback ‘I just wanted to drop you a quick line to say how brilliant the thyroid in pregnancy alert is, with the links to the clinical information advice sheet.’ We are hoping that the protocol will be evaluated by EMIS with a view to it being made available to other practices via the EMIS library. EMIS is an electronic system that allows healthcare professionals to share information.

Thyroid Eye Disease

Over the past few years the BTF and the Thyroid Eye Disease Charitable Trust (TEDct) have worked with expert endocrinologists and ophthalmologists representing professional bodies on a project to bring about improvements for patients with thyroid eye disease. This collaborative work – the TEAMed project – has included questionnaires, data collection and research studies, resulting in evidence from which publications, guidance and practical information, including an assessment tool and a TED early warning card for patients, have been generated.

The TEAMed-5 campaign (see BTF News 97, p3 and www.btf-thyroid.org/TEAMed-5), launched in November 2017 highlights five key points that aim to promote better care for patients with, or at risk of, TED, and these recommendations are regularly promoted to thyroid and eye specialists so they can use the information to benefit their patients. The campaign was presented at the European Thyroid Association meeting in Newcastle in September 2018 and there will be two presentations on TED at the Society for Endocrinology British Endocrine Societies meeting in Glasgow in November 2018. The focus of the 2018 Cambridge Ophthalmological Symposium in September, where Janis Hickey and Lorna Pankethman represented the BTF, was ‘The Thyroid and the Eye’. A summary of the important and ground-breaking research presented during the symposium will be included in BTF News 100.

In recent months, the TEAMed group’s focus has been to highlight the campaign to other specialists, such as orthoptists and optometrists involved in providing treatment to TED patients, and to gain their engagement. An update about TEAMed-5, written by Lorna Pankethman from the BTF, who represents the British and Irish Orthoptic Society (BIOS) on the project, appeared in the August edition of Parallel Vision, the newsletter for orthoptists, and sought feedback on audit standards and joint thyroid / eye clinics in the UK, which will feed into a major survey to help guide the establishment of specialised multidisciplinary TED clinics.

A further article has been submitted for publication in a journal for optometrists; and an article for GPs on Graves’ disease has included guidance about TED (see above report in ‘Hyperthyroidism’).

Looking to the future the aim is to implement TEAMed-5 recommendations across the UK. Plans are being drawn up, and it is expected that an implementation group will shortly be established to manage this three-year project.

If you have been diagnosed with Graves’ disease and have not been given a TED early warning card (http://www.btf-thyroid.org/images/documents/teamed_warning_card.pdf) by your consultant, please send the name of your hospital to teamed@btf-thyroid.org so that we can send them supplies of the card free of charge.

Children

On 19 September Julia Priestley attended a stakeholder meeting in Birmingham with the aim of helping to develop the Strategic Research Priorities in Paediatric Endocrinology. Researchers and clinicians in this area have always struggled to attract NHS and other funding since most of the conditions involved are very rare and so relatively small numbers of children are affected. The meeting was supported by the NIHR and the British Society for Paediatric Endocrinology and Diabetes.

By bringing together all the patient groups and key members of the research community it is hoped that common themes will emerge and the priorities for research needs can be established and developed.

The third BTF Children’s Conference will take place on 8 June 2019 in central Birmingham. We are delighted that we will be working with the paediatric 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. To register your interest in the event please email children@btf-thyroid.org

**BTF Research Award 2019**

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.

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

Deadline: 31 January 2019

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**The Evelyn Ashley Smith Nurse Award**

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

The BTF has funds of £1000 per annum to help cover conference/training expenses, including registration fees and/or travel costs. The value of each award is up to £500. You may apply at any time during the year.

Who can apply?

Endocrine nurses, nurses, midwives and healthcare professionals working in the UK. Full details and an application form are on the BTF website www.btf-thyroid.org/professionals/nurse-award/180-nurse-award-application.
If you are involved in a fundraising event in aid of the BTF please get in touch so that we can send you a fundraising form and help you advertise your event. We can also supply BTF t-shirts and running vests, but please allow enough time for us to post it to you.

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.

If you are employed, please check with your employer to find out whether it operates a match-funding scheme.

**Virgin Sport British 10K London Run**

On 15 July, in what was one of the hottest days of the year, Alexandra McMullan, Reece Avery, James and Katherine Kneebone, Martha Jeffery, Arun Sudhman and Karen Stevens completed the Virgin Sport British 10K London Run.

Karen a former BTF telephone contact says: The atmosphere was brilliant!

People cheering you on, mist sprays to keep you cool and the beautiful sites of London – it really was incredible and up there, as one of my best days ever!

Karen has raised over £700 for the BTF.

Alexandra and Reece were proud to show off their medals after completing the race.

Alexandra and Reece have raised £170 for the BTF.

**Katherine and James** decided to take part in the run because they wanted to support their sister who has Hashimoto’s. Katherine says: We would like to thank the BTF for the great work it does in bringing awareness of thyroid disorders. It was great to do something to support our sister and spread awareness of thyroid disorders.

Katherine and James have raised £170 for the BTF.

**Martha** ran the race with her friend Arun from Hong Kong. Martha says: I wanted to take part in the run because my baby daughter Iris, now 9 months old has congenital hypothyroidism. Our family friend, Arun, on holiday here for a month from Hong Kong, was also inspired to run for the BTF.

Martha and Arun have raised £945 for the BTF.

**Mark Leach** completed one leg of the John o’ Groats to Lands End bike ride. Mark says: This was my first cycle of over 100 miles in one day. My friends and family are proud of my achievement.

Mark raised £85 for the BTF.

**Simon Owenson** ran in the Dundee Runners Adventure Marathon (DRAM) on 15 July 2018. Simon says: I managed to complete the marathon but it was way harder than I anticipated. The temperature on the day was 25+ degrees and I ended up being dehydrated through my lack of experience and not drinking enough at each water station. I completed the marathon in 4 hours and 22 minutes.

Simon has raised £800 for the BTF.

**Joe Plater** set himself another 24 hours solid live streaming challenge in the game Elite Dangerous on the 9 June 2018. Joe did the same challenge last year and raised a fantastic amount for the BTF. Joe who was diagnosed with thyroid cancer in October 2016 raised over £8,000 for the BTF. You can watch the stream on Joe’s YouTube channel: www.youtube.com/c/CMDRPLATER

**Julia Hudd** took part in Wiltshire Big Pledge on 14 May 2018 and in the Rainbow Run on 2 June 2018. Julia says: I was diagnosed with Graves’ disease in September 2017. I decided to take on a variety of challenges in an attempt to raise awareness of thyroid disorders and raise funds for the BTF who are a source of knowledge and information.

Julia has raised £145 for the BTF.

**Rosie Roarty** and her team Jason Brown, Louise Barnett, Siobhan Feasey, Toby Gowen and Andrew Duncan climbed the Yorkshire Three Peaks on the 25 August 2018. Rosie says: I decided to raise money for the BTF after undergoing a total thyroidectomy in May 2018 to treat Graves’ disease. I was diagnosed with Graves and Thyroid Eye Disease in 2016. I used the BTF website frequently during my illness, and wanted to show my appreciation by raising money for them, whilst also raising...
awareness of thyroid disorders and their symptoms. My friends and I completed the Yorkshire Three Peaks challenge in just less than 11 hours, 40km and 61,000 steps each, raising over £1,300 for the BTF.

Ben Hardman took part in the Tough Mudder north west Cholmondeley Castle 10km on the 9 September 2018. Ben says: I really enjoyed it and chose the BTF because my wife has Graves’ disease and I wanted to do my bit to help in anyway I could.

Ben has raised over £200 for the BTF.

On 13 July 2018 Ian Straw (Dad to Joe, see below), prisoners and PE staff from HMP & YOI Doncaster took part in a charity bleep test challenge. Ian says: We completed 10 bleep tests to level 10 with a two minute break in between each test. There were 6 staff and 30 prisoners that took part in this very difficult challenge.

Ian and the rest of the team raised over £400 for the BTF.

Joe Straw, BTF trustee, achieved 3 more fundraising targets of his Five@25 challenge!

On the 23 June 2018 Joe completed his second challenge and climbed the Yorkshire Three Peaks. Joe says: My Dad, three friends and myself completed the Yorkshire Three Peaks. We completed the challenge and, to celebrate, had food in the Pen-y-ghent cafe before driving back home. Although climbing the Yorkshire Three Peaks was a very hard endurance challenge, I would definitely recommend it to others who wish to raise funds for the BTF.

It was really exciting and the views from 15000ft were incredible. I would definitely do it again and recommend skydiving as an unforgettable experience and a great way to raise funds for the BTF.

Joe’s forth challenge was the Arc Triathlon on the 27 August 2018. Joe says: I was able to complete the 450m swim with no problems before heading onto my 25km bike ride in the Peak District. After the cycling was the 6.5km run. I managed to get into a good rhythm and managed a strong finish.

Joe has raised £925 so far for the BTF.

On the 9th of September, sisters Niamh and Aoife Mumph decided to do a bake sale to raise funds for the BTF. Niamh says: We set the event up on the side of the towpath at Stanley Ferry. Our wonderful friends and family donated cakes and money. We also had a tombola that went down a treat. Overall, we raised £280! We decided to do this in honor of our baby sister Saoirse, aged 2, who was diagnosed with congenital hypothyroidism which means she was born with no thyroid.

Thank you to everyone who helped and all the team at the BTF!

Gemma Sheppard took part in the Great East Run on 16 September 2018. Gemma says: I’ve always wanted to try running and thought the half marathon would be a good one to choose. I am not a runner so it gave me a new challenge. I trained 3 times a week for about 4 months, I chose to support the BTF as I have hypothyroidism and I wanted to raise awareness. My children see all too often when I am not feeling well, so I ran this for my children to show them that if you put your mind to something and work hard you can achieve anything!

Gemma has raised £595 for the BTF.

SimplyHealth Great North Run

On 9 September 2018 Marcia Melton, Andrea Robinson, Angela Court-Johnston and daughter Esme completed the biggest half marathon in the UK and the World!

Angela who is a member of the BTF team at head office ran the half marathon with her daughter Esme and friend Andrea. Angela says: We felt very privileged for our first running race, to have participated in the GNR. It was an amazing carnival atmosphere and we were surrounded all of the way by crowds of people, full of good will, kindness and generosity. Even better, we raised money and awareness for a good cause.”

Angela, Esme and Andrea have raised £1,320 for the BTF.

Marcia who was diagnosed with Graves’ disease says: I competed the Great North Run! And did it in 2:19:43, only 5 minutes slower than when I did it 10 years ago. It was tough and took a lot more determination to keep up a steady pace this time. But with the Tyne Bridge, the Red Arrows, the musicians, and the crowds lining the route, it was a great experience and I’m so glad I achieved it.

I ran for the BTF as I have used their resources to support me during my own experience of Graves’ disease. Though it’s been a long journey, the doctors said all would come well, and doing this run has taken me another step (or 26000!) forward.

Marcia has raised £320 for the BTF.
Thyroid disorders and the menopause

The BTF often receives queries relating to aspects of the menopause insofar as they relate to thyroid disease (see Letters, page 10). This article covers the issues around symptoms management and available treatments.

Thyroid and the menopause

As some symptoms of thyroid disease can be similar to postmenopausal symptoms, it’s not unusual for them to be incorrectly attributed to the menopause or even put down to stress. To check the diagnosis, a blood test for thyroid function should be performed.

Hypothyroidism is usually managed by a GP whereas hyperthyroidism will be managed, at least initially, by an endocrinologist in a specialist thyroid clinic. Borderline results may need to be repeated and monitored for a period of time with specialist advice from an endocrinologist.

HRT and phytoestrogens

Some women who experience severe menopausal symptoms due to oestrogen deficiency may be prescribed HRT. Women who have no pre-existing thyroid disorder and have normal thyroid function usually adapt well to the effects of the HRT and their thyroid function remains normal. However, women with pre-existing hypothyroidism treated with thyroxine, may require an increase in their thyroxine dose after starting HRT. Therefore it is useful for thyroid function tests to be re-checked after starting HRT.

Soy foods are a traditional component of Asian diets but their alleged health benefits have been boosted its popularity in recent years and promoted more widespread consumption. Suggested health benefits include alleviation of menopause-related hot flushes and protection against osteoporosis. There are several soybean components that may contribute to the possible health benefits of soy but most attention has focused on the phytoestrogens, leading to the development of phytoestrogen supplements and the fortification of foods with soybean constituents.

Despite the possible benefits, there have been some concerns that soy may adversely affect thyroid function and interfere with the absorption of synthetic thyroid hormone. However there is little evidence that soy foods or phytoestrogen supplements affect thyroid function in people with normal thyroid function. In people with borderline thyroid function and low iodine intake, soy foods may increase the risk of hypothyroidism. Therefore, it’s important for people who regularly consume soy food to ensure their intake of iodine is adequate. There is also evidence to suggest that soy foods may inhibit the absorption of thyroxine and increase the dose of thyroid hormone required by hypothyroid patients.

Women with hypothyroidism who take calcium carbonate supplements should ensure that they don’t take their calcium supplement within four hours of the thyroxine dose. Calcium carbonate may decrease the absorption of thyroxine by nearly a third when these medications are taken at the same time.

Osteoporosis and thyroid

Thyroid hormone plays a key role in maintaining healthy bones. In post menopausal women, hyperthyroidism is a risk factor for sustaining a hip fracture. In part, this is due to the effects of excess thyroid hormones on the cycle of bone production and resorption. Hyperthyroid patients have shorter phases of building bone and longer phases of bone resorption. Hypothyroidism is also associated with an increase in fracture risk. Whether borderline (subclinical) hyperthyroidism is associated with an increased fracture risk remains less certain as there is not sufficient data to draw definite conclusions in all patient groups.

Alternative/complementary treatments for menopause symptoms

Many women who struggle to manage menopausal symptoms choose to avoid taking HRT, or perhaps have a clinical reason not to use it. These people may look to alternative or complementary treatments, such as herbal remedies and bioidentical (‘natural’) hormones. These formulations aren’t recommended for symptoms of the menopause because it’s generally unclear how safe and effective they are. Furthermore the production of them is not subject to the same regulations as Formulary drugs and they may have interactions with other prescribed medicines.

Before starting alternative, complementary or ‘natural’ medicines you should get advice from your doctor or pharmacist.

Conclusions

Thyroid disorders may cause similar symptoms to the menopause. HRT and phytoestrogen supplements don’t seem to affect normal thyroid function, but may reduce the absorption of thyroxine medication in those with hypothyroidism. Women considering taking alternative or complementary medicines for their menopause symptoms should take advice from their doctor or pharmacist.

An earlier version of this article appeared in The Menopause Exchange newsletter. With thanks to Dr Jackie Gilbert, Consultant Endocrinologist, King’s College Hospital, London who helped to write it.

Exercise and thyroid disorders

We are all familiar with the wide range of health advantages that regular exercise can give us. It can relieve stress, improve mood, provide valuable social interactions and help with weight management. All of these benefits of course can counter some of the unpleasant symptoms of thyroid disorders.

Exercise also plays a vital role in protecting people against developing osteoporosis. All men and women are at risk of osteoporosis - everyone starts to lose some bone density from the age of 35 years and this is just a normal part of ageing. It is more common, however, in older women after the menopause, as they stop producing oestrogen, a hormone that protects the bones. After the menopause bone can be lost more rapidly over the next five to ten years.

You can help keep your bones healthy by exercising regularly. Weight bearing, resistance and high impact exercise, such as jogging or power walking, helps strengthen bones. Other exercises, such as yoga, pilates and Tai-Chi, may be useful in improving balance, therefore reducing the risk of falls which could break bones.

Other important advice to protect your bones includes eating a well-balanced diet containing calcium-rich foods, maintaining normal vitamin D levels, avoiding smoking, and keeping your alcohol drinking to within recommended limits.

When people are diagnosed with a thyroid disorder, dealing with the symptoms, and sometimes erratic energy levels can be challenging. But once your thyroid hormone levels are back in control there are lots of very good reasons to incorporate regular exercise into your daily life. You should always be guided by how you feel, your exercise capacity and stamina and if you are in any doubt about what would be the best exercise for you have a chat to your doctor.
**My Story**

**Rosie’s story**

My thyroid disease journey started in 2016. I was 27 and had just left London to live in the United Arab Emirates (UAE) as my fiancé had a new job. I didn’t take much notice of the symptoms I experienced at first. I put the initial weight loss down to the heat of living in the UAE. Then I noticed on my Apple Watch that my resting heart-rate was 95bpm, which I thought was because I wasn’t doing as much walking around as I did in London. Shortly after, my eyes felt gritty and strained when I looked to the side, this was because of sand in the air, I told myself. It was only when my eyes suddenly began to bulge that I realised I was sick.

A blood test confirmed I had Graves’ disease with Thyroid Eye Disease. I didn’t even know what a thyroid really was at this point. My endocrinologist said my thyroid antibodies were off the scale, and put me on Prednisolone (steroid medication) to help the eye inflammation, and also started me on Carbimazole. By this point, insomnia and tremors had kicked in and my resting heart rate was 120bpm, so I was also taking sedatives and Propranolol (beta-blocker) several times a day. I’d suddenly gone from being healthy to needing a pill box to organise the eighteen tablets I was taking daily.

In the next couple of weeks, my face and body started to bloat from the steroids, and then my hair started to fall out. I lost around 70% of the hair on my head, and I was unrecognisable. My fiancé and I decided to move back to the UK at this point so I could be near my family.

My endocrinologist in the UK soon tapered me off of the Prednisolone and the other medications, and my face and body went back to normal. My eyes looked a little better. My thyroid levels stayed stable, and my Carbimazole dosage was continually reduced over the next 18 months until I was no longer taking it. Eventually, my hair grew back too.

After a few months of being stable without medication, my bloods confirmed I was heading for a relapse. I’m actually really grateful that I relapsed quickly, as I felt like the end was in sight. I opted for a thyroidectomy, as I was concerned that radioactive iodine treatment had the potential to worsen my eye symptoms, and I had the operation in May this year. I felt better immediately.

I’d be lying if I said I’d stayed positive throughout this experience, but it’s okay to allow yourself to feel down and have a pity party if you need to, as long as you pick yourself back up again. I remember when things were at their worst, doing my make up in the mirror before work, or catching my reflection in a window, thinking I looked like such a monster. As hard as it was, there was nothing else to do but wipe away the tears and keep going, focusing on the next milestone on the road to recovery.

Following my operation, I felt like it was the right time to do something positive with my experience. I wanted to show my appreciation for the BTF by raising money for them, whilst also raising awareness of thyroid disorders and their symptoms.

My friends and I completed the Yorkshire Three Peaks challenge in August in just under 11 hours, 40km and 61,000 steps each, raising over £1,300. (See BTF fundraising page 6).

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**Letters and Comments**

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

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

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

**No deal Brexit**

**Our members asks:** Since the government has given guidelines about the stockpiling of insulin in the event of the no Brexit deal, I was wondering if there were any guidelines about the stockpiling of levothyroxine T4?

**Our medical advisor replies:** We are not aware of any issues surrounding the supply of levothyroxine but obviously we will keep our members up dated about this issue should the situation change. At the moment supplies are continuing as normal as far as we are aware. No difficulties have been reported to us.

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**Long use of Carbimazole**

**Our member asks:** I was diagnosed with Graves’ disease in early 2014. I have had two, eighteen month courses of Carbimazole and have relapsed, both times.

When I have been on Carbimazole, the dose has been gradually reduced down to 5mg every other day. I have been very stable at that level.

At my last hospital visit to see the consultant, he has put me back on to Carbimazole because I have become hyperthyroid again.

The consultant I saw this time was insistent that I either have surgery or radioactive iodine treatment.

My previous consultant said that in the event of relapse again, because I was stable on such a tiny amount of Carbimazole, he couldn’t see why I shouldn’t be able to continue to take Carbimazole long term.

I am very confused. I don’t want surgery or radioactive iodine treatment. I feel as if I am...
being bullied into it, especially after the comments from the previous consultant.

I would be grateful for any advice regarding the long-term use of Carbimazole at this very low dose. I have had no adverse reactions to Carbimazole.

**Our medical advisor replies:** long-term use of Carbimazole is acceptable and if you do not wish to have surgery then you should make this known. Radioactive iodine, surgery and long-term Carbimazole are all recognised options for the treatment of relapsed Graves’ disease. If you do not wish to have surgery or radio-iodine you should discuss this further with your consultant and, of course, the final decision on what treatment you should or should not have will always sit with you.

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**Congenital hyperthyroidism**

**Our members asks:** I gave birth to my baby boy on 30 March 2018. We were recently told our son has congenital hyperthyroidism and the hospital wanted to do a scan of his throat. We were under the impression it was an ultrasound scan but the paediatrician casually informed us that she would need to put a cannula in his arm to inject some dye.

I am in absolute shock at the diagnosis and I am struggling to come to terms with it. I am really not keen on the dye being injected into his arm. I have recently spoken to a friend of a friend, who has a daughter with the same condition, who said this procedure wasn’t necessary, as their consultant didn’t feel it would alter the treatment plan.

I was wondering if you would be able to give me any more information on this please?

**Our Medical Advisor replies:** I think it is crucially important that you talk to the clinical team at the hospital about this - these are the kind of issues that are best discussed face to face.

There are pros and cons with investigations like this with some units recommending this test and other units less keen. Advantages include the fact that it may help to establish the reason for your son’s thyroid problem - and hence whether it is a permanent problem or not. Disadvantages include the fact that it involves a cannula and a very small dose of radioactivity.

European guidelines see this test as being helpful in the main but it can still be argued that in the short term it does not usually alter the decision to ‘treat’ or not.

Contact the team at the hospital and explain your uncertainty and then have a good discussion with them face to face. Ask them about the role of the ‘dye’ or ‘radioisotope’ test - and the role of other tests such as a thyroid ultrasound.

**Our medical advisor answers the following questions:**

I suffer from hypothyroidism following a subtotal thyroidectomy. I was advised to keep the TSH levels between 0.4 to 1.5 and the T4 at the high side of the normal range. This was achieved by increasing the thyroxine to 125 mg. I am now 57 years old and progressively over the years I have suffered from excessive fatigue. My TSH has remained at 0.4 but my T4 is at the lowest part of the range. Why is this?

This is difficult to explain, however every person has their own balance between TSH and free T4 concentrations. Studies show that TSH is the most stable test over the long-term and that there are risks (on the heart and bones) associated with having a TSH less than 0.4mU/L, and certainly below 0.1mU/L. Aiming for a TSH of 0.4-1.5mU/L is frequently the best target for patients, although every patient is different and this target will not be ideal for everyone. The free T4 levels vary more from day to day than TSH levels, and are therefore thought to be less reliable and less useful in stabilising patients on thyroxine replacement.

**My ferritin level is low at 14. Is there a link between ferritin and thyroid disorders?**

Your ferritin is in the normal range, but at the lower end of the normal range. There is no direct link between a controlled thyroid condition and a low ferritin but there can be indirect links. You need to check if you are eating sufficient foods containing iron, such as vegetables (spinach, beans), liver and red meat. If so, then you would need to consider if you are malabsorbing (abnormality in absorption of food nutrients) your food, this is especially relevant if you are also losing weight. It would be important to know if you are anaemic or have other signs of malabsorption (eg low albumin in which case further investigations may be warranted. Some conditions causing malabsorption are more common in people with thyroid disorders.

If your ferritin levels were low you should also make sure that you are not losing iron - this is usually in the form of blood. Check your urine and faeces for blood loss, and if you have access to bowel screening, make sure you undergo screening as advised.

As mentioned your ferritin levels are in the normal reference range, and there may not be any problem. It may be just a matter of eating more foods that contain iron.

**Could the yellowness of my skin be linked to low ferritin?**

There is unlikely to be any connection between these two in your case.

**I am taking HRT Oestrogen only orally for profound menopausal symptoms and osteoporosis. Would it be advisable to be prescribed Transdermal HRT patches (so as to bypass the liver)?**

Transdermal patches are thought to be more “physiological” because they bypass the liver, and thus are thought to have less side effects. It may be worth trying transdermal patches if your symptoms are not controlled with tablets, but if the tablets were working well it would be advisable to continue with the medication that is already working well for you.

**Haemochromatosis: medical advisor comments:**

Haemochromatosis is one of several conditions involving iron deposition in several body organs including the thyroid and pituitary. Therefore, both primary and secondary (central) hypothyroidism is more likely in this condition. I am not aware of any recent data but prevalence of 10% hypothyroidism in haemochromatosis patients used to be quoted.

I think it is important that people with hypothyroidism are aware of the link especially if there is a family history of haemochromatosis and, likewise, it may be useful for haemochromatosis patients (and their healthcare professionals) to be aware of the link. For more information please go to: [www.haemochromatosis.org.uk](http://www.haemochromatosis.org.uk)
questions and discussion. It was agreed by all that this was an excellent, enlightening meeting.

**Leeds (Wharfedale)**

Next meeting: 31 October 2018, 7pm (doors open at 6.50).
Location: The Memorial Hall, Harrogate Ladies College, Clarence Drive, HG1 2QG.
Speaker: **Dr Peter Hammond**, Consultant Endocrinologist, Harrogate Hospital.
Dr Hammond will be speaking on all things thyroid followed by a Q & A session.
Contact: **Caroline** on 0113 288 6393 or email: cfields237@blinternet.com

Past Meeting: Another successful meeting was held on 25 July. We had a full house and it was good to see old friends.

Of course, there were a lot of new faces too. Many newly diagnosed people attended who were seeking knowledge and answers for their thyroid condition.

**Dr Sam Matthew Pearson**, an Academic Clinical Fellow in Diabetes and Endocrinology in Leeds, gave us a very enlightening and entertaining talk. His knowledge was extensive which was proven by the Q&A session, after his presentation. As usual, questions were still being asked despite the doors having to close at 9pm. Dr Pearson very kindly continued his conversations outside, answering patient questions.

Also in attendance was Angela Court-Johnston from the BTF office who collected donations at the end of the meeting. It was nice to put a face to the voice.

**Milton Keynes**

The Milton Keynes local support group meeting on 6 October 2018 was cancelled
Normal service will be resumed next year 2019.

Next Meeting: TBA.
Location: The Pavilion, Open University, Milton Keynes MK7 6AA.
Contact: **Wilma** on 01908 330290 or see www.thyroidmk.co.uk, find us on Facebook or follow us on Twitter @ThyroidMK.

Past Meeting: On 7 July 2018 we were very fortunate to have **Dr Asif Malik Humayun**, Consultant Endocrinologist, Milton Keynes University Hospital returned to our group to talk about hyperthyroidism. As expected, from our previous experience, a much smaller audience attended.

The talk was very informative and Dr Humayan allowed time for lots of questions and discussions from the audience.

Whether you are newly diagnosed or have a long-standing thyroid condition, come and join our local meetings. Our information events are held regularly with professional and informative speakers. They provide an opportunity to meet with others who have a thyroid condition. We always have professional speakers with a health-related background. They are usually drawn from the local hospital and community health services.

**Start a support group!**

Are you interested in bringing people together to start a BTF support group in your area? If yes, we would be very interested to hear from you. For further information please email: info@btf-thyroid.org

For other volunteer opportunities please visit our website: www.btf-thyroid.org or telephone 01423 810093 and we will be happy to hear from you.

**Join the BTF online!**

Don’t forget it is now possible to join the BTF online. We hope this will make it easier for existing members and encourage new members to sign up.

Since beginning online membership we’ve had more than 50 additional members than the same period last year.
**BTF LOCAL COORDINATORS**

- **Bristol** Michelle (U)  
  michelle.griffiths@live.uwe.ac.uk (for local group information only)
  
- **Cambridge** Mary (O,RI,U)  
  butterflyecho@hotmail.com
  
**Milton Keynes** Wilma (U)  
07704 229169

**Edinburgh** Margaret (PC)
0131 6647223

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

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**BTF TELEPHONE SUPPORT CONTACTS**

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

<table>
<thead>
<tr>
<th>Volunteer</th>
<th>Telephone Number</th>
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<tbody>
<tr>
<td>Dave (PC,CS,RAI)</td>
<td>07939 236313</td>
</tr>
<tr>
<td>Jackie (PC,CS)</td>
<td>01344 621836</td>
</tr>
<tr>
<td>Gay (G,TS)</td>
<td>020 8735 9966</td>
</tr>
<tr>
<td>Angela (U)</td>
<td>01943 873427</td>
</tr>
<tr>
<td>Karen (U)</td>
<td>01628 529212</td>
</tr>
<tr>
<td>Ann (GR,RI,TS,TED)</td>
<td>01642 300709</td>
</tr>
<tr>
<td>Joan (U)</td>
<td>01392 874517</td>
</tr>
<tr>
<td>Maria (U)</td>
<td>020 87934360</td>
</tr>
<tr>
<td>Jane (GR,RI,TED,G,U)</td>
<td>01737 352556</td>
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<tr>
<td>Peter (TED,GR)</td>
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<tr>
<td>Penny (Ch)</td>
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<td>Kellie (C)</td>
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<td>Kate (Ch)</td>
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**KEY**

- ☀ 2 to 5pm Monday, Tuesday and Thursday
- ☀ 2pm to 5pm Wednesday and Friday afternoon
- ☀ After 6pm weekdays and anytime weekends
- ☀ Wednesday, Thursday and Friday 7pm – 10pm
- ☀ Before 7pm
- ☀ 9am to 5pm weekdays, 10am to 5pm weekends
- ☀ 10am - 2pm Mon -Thurs only

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

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**OUR PARTNER ORGANISATIONS**

- **AMEND** The Association for Multiple Endocrine Neoplasia Disorders
  Tel: 01892 516076  [www.amend.org.uk](http://www.amend.org.uk)

- **Butterfly 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)

- **Hypopara UK** Helpline: 01342 316315  [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 Association**  [www.british-thyroid-association.org](http://www.british-thyroid-association.org)

- **British Association of Endocrine and Thyroid Surgeons**  [www.baets.org.uk](http://www.baets.org.uk)

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**CURRENT MEMBERSHIP RATES**

<table>
<thead>
<tr>
<th>Members living in the UK</th>
<th>By cheque</th>
<th>By standing order</th>
<th>Lifetime membership £200 by cheque</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Full: £25 per year</td>
<td>Full: £25 per year</td>
<td>By cheque from a UK bank account</td>
</tr>
<tr>
<td></td>
<td>Concession: £15 per year</td>
<td>Concession: £15 per year</td>
<td>By standing order through a UK Bank</td>
</tr>
</tbody>
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Concession: If you are retired you may wish to pay the concessionary rate. Please help us by ensuring that you pay the correct subscription.

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**A Merry Christmas and a Happy New Year to all our Supporters From the BTF Team!**

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**The British Thyroid Foundation, Suite 12, One Sceptre House, Hornbeam Square North, Hornbeam Park, Harrogate HG2 8PB**  
Tel: 01423 810093  [www.btf-thyroid.org](http://www.btf-thyroid.org)  
Office enquiry line open: Mon to Fri: 9.30am - 4pm.