BTF to take part in the Big Give Christmas Challenge 2014!

We are delighted to announce that the BTF has been selected to participate in the Big Give Christmas Challenge, an annual matched funding event in which online donations from the public will be matched.

Over the last six years the Big Give Christmas Challenge, which was funded by the Reed Foundation in 2007, has become the UK’s largest matched funding challenge, and has raised over £50m for hundreds of charities throughout the UK. Small charities in particular benefit by gaining exposure they would never otherwise be able to achieve.

This is the first time the BTF has run a fundraising appeal and the opportunity to do it with the support and profile of the Big Give is unmissable. If successful the challenge will raise the funds to print and distribute BTF’s reviewed and updated patient information that is invaluable to so many patients and their families.

How does the challenge work?

Matched funds – comprising money from UK trusts, foundations, corporations and philanthropists - will be released at 10am GMT on the morning of the 4, 5 and 6 December. Online donations are matched on a first come, first served basis and your online donation will be matched as long as there are matched funds still available. The Christmas Challenge will conclude once all of the matched funds have been exhausted.

How can I donate during the Christmas Challenge?

To have a chance of making a matched donation and ensuring that your money goes further, you must be ready to donate on line as close as possible to 10am on 4, 5 or 6 December. The allocated matched funding will probably run out quickly each day so the closer to 10am you can get on line and donate the better!

- Go to www.thebiggive.org.uk
- Search for the British Thyroid Foundation in the ‘keyword’ box and click on ‘Donate Online’ to make your donation.

Please note that to take part in this challenge donations must be made on line. If you are not able to donate on line you can still give money to the BTF in the traditional way! If you have any questions about this challenge please email julia.priestley@btf-thyroid.org or call her on 01423 709707.

Did you know:

Thanks to our members the BTF has been able to contribute over £200,000 to thyroid research via the BTF Research and Nurse Awards since 1997.

BTF regularly participates in research studies and working groups to ensure the patient’s perspective remains paramount.

We are frequently approached to support applications for funding and readily do so where it is clear there is patient benefit.
The British Thyroid Foundation, 2nd floor, 3 Devonshire Place, Harrogate, North Yorkshire HG1 4AA
Tel: 01423 709707 or 01423 709448
website: www.btf-thyroid.org

In the event of a complaint, please address your correspondence to ‘The Chair of Trustees’.

Director and Secretary to the Trustees: Mrs J L Hickey
Treasurer: Professor Mark Strachan
Computer Manager: Professor B Hickey
Editor: Liz Clegg e.clegg@btf-thyroid.org
Medical Editor: Dr Petros Perros
Editorial Board: Nikki Brady, Mr Daniel Ezra, Professor Simon Pearce, Dr Petros Perros, Dr Peter Taylor, Dr Mark Vanderpump
Webmaster: Claire Skalski
PA to the Director and Office Manager: Mrs Cheryl McMullan c.mcmullan@btf-thyroid.org
Development Officer: Julia Priestley julia.priestley@btf-thyroid.org
Clerical Assistant: Helen Dawson
Head Office Volunteers: Jan Ainscough, Angela Hammond, Vivienne Rivis, Fiona Maxwell


Copyright © 2014 British Thyroid Foundation. All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means without the prior permission of the copyright owner.

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

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

If you have any comments or queries regarding this publication or on any matter concerning the British Thyroid Foundation we would be pleased to hear from you.

News About BTF

BTF films
BTF has developed some short films on patient experiences of thyroid disorders with Coast (www.coasthouse.com) - a film company that has successfully worked with charities to raise awareness around key health issues. The aim of the BTF films is to help inform and support people who are facing a diagnosis or starting treatment by telling positive stories. The films will be on our website shortly and cover hypothyroidism, hyperthyroidism and thyroid cancer.

BTF Facebook groups
Helping to create a network of families who can support one another with useful information is one of the objectives of the Children’s Project. Earlier this year we set up a closed Facebook group as a way of bringing parents together and we know that the forum is being well used.

In response to calls from members and others we have now set up closed Facebook groups for people with hyperthyroidism and thyroid eye disease. The groups are called BTF Hyperthyroid Group and BTF Thyroid Eye Disease Group. They are secure sites and posts on them can only be seen by members of the groups. If you would like to join please email julia.priestley@btf-thyroid.org

Patient leaflets
We have reviewed and updated our patient leaflets and these will shortly be available online. Go to www.btf-thyroid.org/index.php/thyroid/leaflets

Share your stories
We would love to hear about your own experiences of thyroid disorders. Our website has a section called ‘Share your Story’ for thyroid patients to share positive thyroid experiences with others. If you have had a difficult experience coping with your thyroid condition but have come through it and can offer hope to others then please let us know by emailing my-story@btf-thyroid.org

Your stories and experiences are not only inspiring but are useful teaching tools and can potentially help further research and funding into thyroid disorders. The Society of Endocrinology recently contacted us for case studies to go in their career booklet for young endocrinologists and we were able to point them towards this page on our website. The European Readers Digest has also been in contact and has asked to use a couple of case studies for an article they will be writing on tiredness.

Email addresses
Please get in touch with us if you would like to receive future newsletters by email, an option we are currently exploring. If you joined before 2013 please email your name, postcode and house number to info@btf-thyroid.org with the heading ‘Electronic Newsletter’. Thank you to all those who have already emailed in expressing an interest in receiving information electronically – we will assume you are happy to receive your newsletter electronically in the future unless we hear otherwise.

Survey on fatigue in people who have an underactive thyroid

A team of researchers led by Dr Nikki Coghhill, a researcher at The Centre for Academic Primary Care (CAPC), University of Bristol, is undertaking a survey on the role of physical activity in addressing fatigue in people who have an underactive thyroid. CAPC is involved in sourcing funding, conducting research and publishing the results of this, in order to contribute towards helping patients receive better care and treatment on a day-to-day basis.

The survey can be completed anonymously on line and is active until mid December 2014. Full details of the survey are available on our website www.btf-thyroid.org under ‘News’ or go to: www.survey.bris.ac.uk/meded/fatiguehypo/

Please note the researchers are unable to provide any personal advice on your condition.

Thyroid cancer guidelines

The BTA (British Thyroid Association) has produced new guidelines on the
management of thyroid cancer. The intention is to provide guidance for all those involved in the management of patients with differentiated thyroid cancer (DTC) and some of the rarer thyroid cancers.

The three main aims of the guidelines are:
- To improve the referral pattern and management of patients with thyroid cancer;
- To improve the long-term overall and disease-free survival of patients with thyroid cancer;
- To enhance the health-related quality of life of patients with thyroid cancer.

In conjunction with the guidelines patient literature has been produced, which is available on the BTF website: www.btf-thyroid.org/index.php/campaigns/thyroid-cancer/bta-cancer-patient-leaflets


**Thyroid Federation International endorses ETA statement**

The BTF as a member of Thyroid Federation International (TFI) has endorsed the recent statement from the European Thyroid Association (ETA) on thyroid hormone substitution: T4/T3 combination treatment and animal thyroid extracts.

The statement clarifies the TFI’s stance on T4/T3 combination treatment and animal thyroid extracts after concerns that many people with thyroid disease feel that their symptoms are not well controlled and that information available in the media is often confusing. The statement also contains background and practical information about combination treatment of T4 and T3 based on the ETA guidelines. The full Alternative Substitution Statement can be found at www.btf-thyroid.org/index.php/thyroid/statements

**Carrots NightWalk**

Sixteen hardy carrots raising money for the BTF took part along with hundreds of other walkers in the annual Carrots Nightwalk – night time walks around London and Birmingham. The walks are organised by Fight for Sight (FFS) to help raise funds for research to prevent sight loss and treat eye disease. Money raised by the BTF ‘bunch’ will help fund a research project into Thyroid Eye Disease (TED).

TED sufferer Faye along with her mum Felicity and friend Lisa completed the 15-mile walk in deteriorating weather and raised nearly £850. Faye said: ‘We left the start line with a cheer, passing the orange balloons and on into the night. Trafalgar Square was our first rest stop with carrot cake on the menu! My favourite part of the walk was of Tower Bridge lit up in purple and blue and walking along the embankment in the early hours - what a sight to behold! The volunteers along the route were wonderful - clapping and smiles spurred us to the finish line as the heavens opened and the rain came down!’.

Lisa added: ‘It was great to have the chance to give something back to a charity that had introduced us. We had a great evening and barely stopped talking!’ So far they have raised over £1000!

BTF founder, Janis Hickey and her husband Bryan along with friends Brian and Jane Simber - who took part in last year’s 15 mile walk - were joined by Eleanor and Matthew Hickey for the six mile walk this year. They set off with other carrots at a fast pace and completed the course in just under two hours. Janis said: ‘London at night was beautiful... and hot (about 25 degrees!) but at least the rain held off for us’. They have raised over £3000.

Nicola Dunlop, an Advanced Nurse Specialist at Moorfields Eye Hospital and last year’s winner of the Evelyn Ashley Smith Nurse Award (see page 11) completed the 15 mile walk with her son Ernest and raised nearly £450. Nicola said: ‘The sights were spectacular and it was my pleasure to support the wonderful work the BTF and FSS do’.

A team of orthoptists from Moorfields Eye Hospital also took on the challenge and raised nearly £750! They were Leena, Siobhan, Amrit, Gillian and Roisin (pictured left to right below) www.justgiving.com/carrots-patch-kids

**TED sufferer Faye** and friend Lisa completed the 15-mile walk in deteriorating weather and raised nearly £850. Faye said: ‘We left the start line with a cheer, passing the orange balloons and on into the night. Trafalgar Square was our first rest stop with carrot cake on the menu! My favourite part of the walk was of Tower Bridge lit up in purple and blue and walking along the embankment in the early hours - what a sight to behold! The volunteers along the route were wonderful - clapping and smiles spurred us to the finish line as the heavens opened and the rain came down!’.

Lisa added: ‘It was great to have the chance to give something back to a charity that had introduced us. We had a great evening and barely stopped talking!’ So far they have raised over £1000!

So far in total £7,000 has been raised for BTF’s £7,500 contribution towards the award, and donations are still coming in. FFS will match-fund with £7,500 for the joint award. If you wish to donate to support thyroid eye disease research please visit www.justgiving.com/janisHickey

The winner of the Fight for Sight/British Thyroid Foundation Small Grant Award 2014 is Mr Daniel Ezra, who is a Consultant Ophthalmologist at Moorfields Eye Hospital NHS Trust. See page 11 for a description of the study.
Out And About

Meetings with Eisai

The BTF was invited by pharmaceutical company Eisai to attend a media advisory board in London in August 2014. The purpose of the meeting was to raise awareness of the ‘Differentiated Thyroid Cancer’ (DTC) patients who are resistant to the radioiodine ablation treatment to destroy any residual, metastatic or recurring DTC. Eisai were looking for a radioactive iodine refractory differentiated thyroid cancer (RR-DTC) patient representative which proved difficult to find so Janet Prentice, BTF Trustee, was invited by Eisai to give a talk ‘from the patient perspective’ at a ‘lunch and learn’ event at the Eisai EMEA Knowledge Centre in Hatfield. There were about 80 staff working in a wide range of departments at the event. The talk was well received, and several staff came up to talk and ask questions afterwards.

In September Judith Taylor, BTF Chair of Trustees, was invited by Eisai to give a talk on behalf of the BTF on ‘thyroid cancer and the patient perspective’ at a ‘lunch and learn’ event at the Eisai EMEA Knowledge Centre in Hatfield. There were about 80 staff working in a wide range of departments at the event. The talk was well received, and several staff came up to talk and ask questions afterwards.

The high interest was because Eisai has recently filed an application to the European Medicines Agency (EMA) for the use of a new drug to treat thyroid cancer. Although treatment is possible for most types of thyroid cancer, there remains a need for treatment options in cases where the disease has progressed. The new drug is called Levatinib, a tyrosine kinase inhibitor, which has been developed to treat RR-DTC. Following completion of the SELECT study, Eisai has filed applications in the USA and Europe for the drug. The data from the SELECT trial were presented by Professor Martin Schlumberger (France) at the American Society for Clinical Oncology meeting in May this year.

The path to Santiago and the European Thyroid Association conference

In September Judith Taylor, BTF Chair of Trustees, joined a group of around 40 people, most of whom were thyroid cancer survivors, on a five-day walk along the final stretch of the Camino de Santiago or ‘Way of St James’. The project ‘Voices on the Path’ aimed to raise awareness of thyroid cancer in Spain, and was organised by the Spanish thyroid cancer patient association AECAT.

Judith said: ‘The journey was an unforgettable immersive experience. There are memories that will stay with me for ever of the camaraderie, the stories, the tears and triumphs, helping each other along the way, sleeping in bunk beds, and sharing ‘pulpo’ (the local Galician octopus dish which is an acquired taste that I have yet to acquire).

Most of all I will remember the triumphant march into Santiago de Compostela on the final day – our numbers swelled by dozens of supporters and local AECAT members - the main square a sea of purple, the flash mob dancers, where we were welcomed by Clara Alvarez, an endocrinologist and local chair of the European Thyroid Association conference which was beginning the following day.’

The European Thyroid Association (ETA) is a professional body concerned with promoting research and training for health care professionals working in thyroid disease in Europe. Their annual meeting in Spain was a five-day event. After completing the walk Judith manned a stand at the conference on behalf of the Thyroid Cancer Alliance (as a representative of BTF). The stand was alongside the Thyroid Federation International (of which the BTF is also a member) and AECAT. Judith noted that the patient organisation stands were extremely busy and visitors to the stands commented on how well the patient organisations work together and on the growing recognition from the medical professionals.

Conference sessions this year included several symposia on thyroid cancer. There was special attention for the emerging class of targeted drugs, tyrosine kinase inhibitors, which hold promise for treating RAI-refractory differentiated thyroid cancer and advanced medullary thyroid cancer. There were also sessions on thyroid disease in pregnancy and childhood, on thyroid replacement ‘failure’, reports on studies into malabsorption issues due to, for example, gluten and lactose intolerance, and on new preparations that may improve absorption of levothyroxine, such as a soft gel capsule that is being evaluated in Italy. British speakers included Colin Dayan (current ETA Secretary), Graham Williams, Peter Taylor, Kate Newbold, John Lazarus, and Margaret Rayman.

Peter Taylor, Welsh Clinical Academic Trainee at Cardiff University and joint winner of the BTF Research Award 2014 commented: ‘One striking aspect I noticed was the increase in the number of presentations relating to hypothyroidism compared to previous years. In particular there were several presentations relating to key aspects of hypothyroidism management, including, combination therapy with tri-iodothyronine, the management of hypothyroidism in pregnancy, how to manage poor absorption of levothyroxine as well as key debates on the management of subclinical thyroid disease. This is an encouraging sign of greatly increased research interest in this area, which in turn should lead to improved therapies and hypothyroidism management. The future of hypothyroidism management does look brighter.’

Thyroid Cancer Alliance stand at the ETA
Projects Update

Hypothyroidism

The Hypothyroidism Care Strategy was developed by BTF as a three year programme to improve support for hypothyroidism patients who make up the majority of BTF members. Launched at the end of 2013, its aims are to focus on improving communication between hypothyroidism patients and their healthcare professionals, including GPs, nurses and pharmacists. So far the following has been undertaken:

A poster and leaflet campaign with a list of hypothyroid symptoms displayed in over 1,200 GP surgeries across the UK has resulted in an increase in calls to BTF HQ and an increase in membership from the parts of the country where the information was displayed, plus requests from GP practices for further information from BTF. There has also been a 250% increase in hits to the BTF website in this period compared with the same period last year. IDS UK who organised the posters have kindly agreed to continue the free campaign until November 2014.

Representatives from the BTF have recently met with representatives from the Medical department of Amdipharm Mercury Company Limited (AMCo), a pharmaceutical company, to discuss patients’ experiences of hypothyroidism and in particular in relation to challenges some have with their medication.

The BTF has worked with a GP who wanted to update a GP training module, which appeared in PULSE Learning (the most widely used training module amongst GPs) about hypothyroidism, including how to manage subclinical hypothyroidism and managing hypothyroidism in pregnancy.

The 2015 BTF Research Award of £20,000 will be specifically for a study into hypothyroidism (See page 9)

A short case study film on patients experiences of hypothyroidism has been produced by film company Coast and will shortly be available to view on the BTF website (see page 2).

As a member of Thyroid Federation International, the BTF has endorsed the International, the BTF has endorsed the Amipher Mcury Company.

Thyroid cancer

The thyroid cancer group has met twice this year and agreed on a definition of its aims and purpose being: ‘To provide support to all thyroid cancer patients and their families, through providing current, evidence-based information and emotional support, through our literature, website, and telephone contacts network, to work with medical advisors to achieve these aims, and to complement the activities of other thyroid cancer patient support organisations in the UK.’

The group met to discuss and provide feedback on the thyroid cancer films which will be launched shortly (see page 2) and also made plans for revising the thyroid cancer booklet, including incorporating more patient stories, and ensuring that the booklet is aligned with the new British Thyroid Association guidelines (see page 2).

The group will next compile an FAQ/briefing about the new class of drugs, tyrosine kinase inhibitors, for treatment of advanced thyroid cancer.

The BTF regularly gets questions about travel health insurance, particularly from people with thyroid cancer and we will be compiling a list of useful information and contact details on this.

Thyroid Eye Disease

Following the publication of its first Executive Report (see: www.btf-thyroid.org/index.php/campaigns/teamed) TEAMeD (the Thyroid Eye Disease Amsterdam Declaration Implementation Group UK) has continued its work to bring about improvements for patients with thyroid eye disease. The following components of the project are in hand:

Preparation of information about the early signs of thyroid eye disease via a ‘warning card’ for patients diagnosed with Graves’ disease about the possibility of developing thyroid eye disease.

Preparation of information about the effects of smoking on thyroid eye disease (see below).

Royal College of Physicians Guidance document prepared by TEAMeD on optimal management of patients with thyroid eye disease is in the final draft stage.

Discussions are underway about a network model for management of thyroid eye disease under NHS England specialised commissioning services.

We wish to thank everyone who took part in the BTF web-based survey on smoking and thyroid eye disease, and who provided invaluable information. We are now in the process of amending the document. If you are a smoker and TED would like to be involved in giving further feedback, please contact Janis Hickey: j.hickey@btf-thyroid.org with the subject line: TED Smoking information

Hyperthyroidism

In the February newsletter (BTF News 85, Page 11), we announced that BTF has been invited by Apitope to be involved in its Graves’ disease project. BTF’s role will be to provide advice and insight into clinical plans from the patient perspective. In June, Apitope announced that through its innovative discovery platform, it has selected a product candidate, ATX-GD-459 that has the potential to treat and prevent the production of stimulating antibodies against TSHR (thyroid stimulating hormone receptor) that lead to Graves’ disease. The development of ATX-GD-459 is part of the DAVIAD project co-financed by the European Commission in the 7th Framework Programme, FP7-HEALTH-2013-INNOVATION-1, 602779. The DAVIAD consortium is comprised of Apitope as coordinator, GlaxoSmithKline Biologics SA, Quintiles Benefit and KWS Biotest Limited.

In the upcoming months, the DAVIAD team will be working towards completing the wide range of activities that must be completed before the first clinical trial with ATX-GD-459 can commence. This first clinical trial is scheduled for 2015.

Further information about the DAVIAD project and the consortium members can be found on the DAVIAD website: www.daviad.eu
Fundraising And Donations

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

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

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

Naomi Leacock and Jo McGurk took part in a ‘Total Warrior’ Event in August and raised a fantastic £500 (£150 of which was kindly donated by their employer, AXA). They decided to raise money for the BTF as one of their colleagues at work has been battling thyroid cancer for some years now and is still undergoing treatment.

They said: ‘Watching him go through the pain of the treatment but still smiling every day and partaking in as much work as he can has provided us with a real reason to embark on this journey. We decided to fundraise for the BTF because we hope that we can make a difference and be able to give others the opportunity that we have to live their lives as we do’.

They said the Total Warrior event was ‘amazingly good fun’ and would definitely recommend it as a challenge!

Emily Heseltine completed the Bristol Half Marathon in September and raised a fantastic £800! Emily said: ‘I’ve suffered with Graves’ disease for six years and after receiving radioactive treatment last summer I’m almost completely cured. For every day I’m able to complete a full day at work AND go out in the evening, I feel like the luckiest person alive! This is why I wanted to put my full health to good use and I am so pleased to have been able to raise £800 for the BTF. To any fellow sufferers, hang in there, it will get better’.

Neil Rutherford raised £350 by taking part in his first ever half marathon, The Great Cumbrian Run in October. Neil said: ‘For years I’ve broken my drunken New Year’s resolution to run a half marathon. But after seeing a photo of myself with my newborn daughter last year I became determined to lose weight, get fit and make her proud of me.’ Neil’s daughter was diagnosed with congenital hypothyroidism soon after birth. Neil’s sister Katrina is also completing some exciting challenges to raise funds too (see future fundraisers below).

Six runners took part in the annual British 10k Run in London in July. Five of them were from the BTF London local group: Denise Sims, Cathryn Holman, Natalie Lofting, Julie Lofting and Karen George. Between them they managed to raise over £800! They decided to have a teddy bears picnic with their supporters and members from the London group after the race so they decided to run with them too! After the run they said: ‘We all made it round and had a fantastic experience’.

Four intrepid cyclists took part in the Great Manchester Cycle in the summer - a 26- or 52-mile ride around the centre of a (traffic free) Manchester. Ian Wolfendale and Andy Fox participated in the 52 mile ride. Ian said after the event: ‘We really enjoyed the bike ride, it was hard work but a fantastic atmosphere’. Wendy Driver (pictured on the left) and Marcela Vickerstaff (on the right) took part in the 26 mile ride, which they both thoroughly enjoyed. They have so far raised £180 for the BTF.

Kevin Savage ran the Great North Run in September and raised £150. Kevin choose the BTF because his nephew Jamie suffers
from a thyroid condition. Kevin said: ‘By far, this was the biggest challenge I have ever set myself. For those who know me well, you will know I can barely run up the stairs!’

Sandra Banfield took part in a 13 mile walk/run/cycle event around Lake Vyrnwy in Wales with her local running group ‘The Dolly Mixtures’ in August. She suffers from Graves’ disease, and she has had a frightening and painful journey back to good health. She raised over £500!

Rebecca Anderton ran the York 10K in August and raised £170. She was diagnosed with hypothyroidism three years ago and is keen to raise as much as she can for a cause close to her heart. Rebecca said: ‘I was really pleased with how well it went, I managed to knock 05:26 off my previous personal best and finished with a time of 1:04:07, which was a big achievement for me to say it was my first race in a year, and the first one back after injury! Another runner even came up during the run to have a chat about the charity as well because she’d been diagnosed with Graves’ earlier this year’.

Catherine Preedy took part in the Cardiff Half Marathon in October after being diagnosed with hypothyroidism three years ago. She said: ‘It was amazing but hard work. I ran with my friend Kate Hatch and we kept each other going through all of it and I wouldn’t have been able to complete it without knowing that I was running for such an amazing charity’. Catherine had a total thyroidectomy two days after the race. She has just gained a place in the London Marathon 2015 and will be raising funds for the BTF again then.

Sam Reeves completed the Tough Mudder in August which is a 12 mile obstacle course involving fire, water, electric shocks, splinters, tight spaces, lots of running and loads of mud! Sam raised £262 and ran for the BTF as his wife was diagnosed with and has beaten thyroid cancer.

Steve Robb, a veteran fundraiser for us, has now undertaken an incredible three marathons and a half marathon in 2014 and raised £250 this year so far. His daughter Ellidh was born with congenital hypothyroidism and Steve is determined to raise as much as he can for the BTF. So far he has run in the Alloa Half Marathon in March, the Manchester Marathon in April, the Strathearn Marathon in June and the Highland Perthshire Marathon in September.

Syz Goss has raised nearly £350 so far by taking part in ‘The Spartan Race Trifecta’ in September and October 2014. This consists of three events, a 3+ mile, 8+ mile and 13+ mile obstacle race (which have to be completed in a calendar year to gain the trifecta!). Syz’s daughter Tiffani was born without a thyroid gland but has had a relatively normal childhood thanks to early diagnosis and support. Syz said: ‘Information and support from the BTF has given us the knowledge to understand some of the hurdles she has had to overcome in her development from baby through to teenager, and now I wish to pay them back by raising as much as I can. The races have been excellent and I actually managed to be placed in the top 200 out of over 3,000 entrants in the races!’.

Syz Goss

Future Fundraisers

Katrina Rutherford who ran the Shanghai Half Marathon for the BTF last year has decided to take on four challenges this year as her baby niece has congenital hypothyroidism. She will be climbing Mount Huangshan solo (that beautiful one in the film Crouching Tiger Hidden Dragon), climbing all 2,726 steps of the Shanghai World Financial Center (also known as the ‘bottle opener’ building and the highest viewing platform in the world) and running the Yangpu 8K run - a warm up for the 2014 Shanghai International Half Marathon!

www.justgiving.com/Katrina-Rutherford

Charlie Scammell is taking part in a 5k Santa Fun Run in December. He was diagnosed with Graves’ disease in 2012 and this year he has gone through radioactive iodine therapy and is now underactive.

www.justgiving.com/SantaFunRun5k

Greg Bolt is taking part in the Southampton Marathon in April 2015.


Donations

Many thanks for your generous donations. We are grateful for them all, including those donated on line, often in response to advice and support from our telephone contacts, local coordinators and BTF head office and also for donations by members at the time of joining BTF or at renewal time.

Peter Foley, former trustee of the BTF, married Elizabeth Dean on 26 September and requested that the guests donate money to the BTF rather than buy gifts. So far an amazing £500 has been donated.

Syz Goss

The Rotary Club of Kenilworth has donated £1,000, raised by nominating the BTF as one of their ‘President’s charities’ and through a fun run.

The Rotary Club of Kenilworth

Peter Foley

Ice Bucket Challenge

Thank you to all our brave supporters who took part in the popular ‘Ice Bucket Challenge’ for the BTF (including Cheryl from BTF HQ!), Member Gill Hedley sent in a £10 donation after her son-in-law Glenn did the challenge by immersing himself in Lake Pukaki in New Zealand which is fed by snow melt! Fundraiser Syz Goss (above) also put his own twist on the challenge and sent us this fantastic picture!
Faye developed Graves’ disease in the summer of 2010 which later started attacking both eyes leading to thyroid eye disease. Here she explains her difficult but ultimately positive journey with the disease.

I was hit with hyperthyroidism in the summer of 2010 not having clue that it had been coming on years beforehand. I remember the day so clearly, I was just a ‘normal’ 26 year old, working hard and getting on with my life. I had suffered post traumatic stress in 2006 which started it all.

I would walk 35 minutes to work each day, there and back, and was in my view, healthy. I achieved an MA a year before and completed my gold DoFE, a fitness challenge if ever there is one! However my walking to work started to become more and more difficult and I was getting so hot and breathless after any strenuous activity. Every morning I would arrive noticing it was getting down. I was getting comments about my weight loss too which I laughed off. It all came to a head one afternoon when I felt like my heart was about to burst through my chest. I slid down a garden wall and really thought that was it. The half hour walk that day took me well over two hours. Whatever it was uncontrollable.

After a year of medication I was still unstable and exhausted. I have slept my late 20s away. A year later another doctor decided it was a ‘one off’ and to stop all my medication. The following week my shaking came back with great force and my immune system started to ‘attack’ my eyes. I didn’t notice until one of the parents of the children I teach said my left eye looked wide, then one of the kids said the same thing, ‘what is wrong with your face miss?’ My eye was being pushed out and my lid had risen showing the whites around my eye.

The blood tests came back with the results.

I was given the option of having my thyroid totally removed in February 2012, which I jumped at, as radioactive iodine would not be an option whilst my eyes suffered. I was given the option of having my thyroid patch covering my hidden secret. I could not stand mirrors even with an eye patch and so started the staring and name-calling: (‘Eye eye’ was the normal comment.) I could not hide my mirrors even with an eye patch covering my hidden secret.

The specialist eye consultant at my local clinic. The irritation was becoming unbearable and I couldn’t sleep, as the eyelid could not close, so my eye would just weep constantly. Then the words – ‘you have Graves’ disease’ came soon after. I had no idea what it was or what it meant until it was explained to me though the tears. More medication with the consequential ups and downs, mood swings, more tears - anything would set me off. I was noticeably angry, bad tempered, and always tired to the point of exhaustion.

I began to wear sunglasses and an eye patch and so started the staring and name-calling: (‘Eye eye’ was the normal comment.) I could not stand mirrors even with an eye patch covering my hidden secret.

The blood tests came back with hyperthyroidism. The doctor called, saying my levels were so dangerously high they needed to check for thyroid cancer and to come in straight away. The results were negative for cancer but my thyroid levels were uncontrollable.

A year later another doctor decided it was a ‘one off’ and to stop all my medication. The following week my shaking came back with great force and my immune system started to ‘attack’ my eyes. I didn’t notice until one of the parents of the children I teach said my left eye looked wide, then one of the kids said the same thing, ‘what is wrong with your face miss?’ My eye was being pushed out and my lid had risen showing the whites around my eye.

So, more tests, more pain, no sleep, weeping, and constant checks at the eye clinic. The irritation was becoming unbearable and I couldn’t sleep, as the eyelid could not close, so my eye would just weep constantly. Then the words – ‘you have Graves’ disease’ came soon after. I had no idea what it was or what it meant until it was explained to me though the tears. More medication with the consequential ups and downs, mood swings, more tears - anything would set me off. I was noticeably angry, bad tempered, and always tired to the point of exhaustion.

I began to wear sunglasses and an eye patch and so started the staring and name-calling: (‘Eye eye’ was the normal comment.) I could not stand mirrors even with an eye patch covering my hidden secret.

The specialist eye consultant at my local hospital made me feel that I was totally wasting her time. I had no hope, no life and I just wanted to curl up in a dark corner somewhere and fade away.

I was given the option of having my thyroid totally removed in February 2012, which I jumped at, as radioactive iodine would not be an option whilst my eyes suffered. I understand I will always have hyperthyroidism. So I have gone from one side to the other. This time the weight I had gained fell away then increased uncontrollably. My thyroid doctor was wonderful and explained everything. She sent me to a knowledgeable surgeon who undertook the operation. However, six months later the other eye started pushing out, then double vision took hold. I had to stop driving; I stopped seeing friends and retreated from life.

Then came the light - my latest and insightful operations. Graves’ disease stripped me of who I was, both within and without, who I was to the world, but I have come through it stronger and have hope - I’m getting married in 2015.

I would like to thank my loving family whose lives I have affected too and my dear friend Lisa who is the same age as me and has gone though it all too. I hope reading my account will go towards a little more understanding and care towards people who look different. If you walk past someone and are tempted to stare or comment, change it to a smile or a kindness, so the whole world becomes that much more bearable.

Faye took part in the Fight for Sight Carrots NightWalk in September with her friend Lisa and mum Felicity and raised nearly £850. (See page 3). Faye met Lisa two years ago at a TED patient event organised by Moorfields Eye Hospital and they have supported each other throughout their illness. Lisa says: ‘It was comforting to finally meet and communicate with someone who knew exactly how I felt as opposed to sympathetic friends and family who could only ‘imagine’ how I felt. Here was Faye who just got it. I instantly felt less alone and we have become a tremendous support system for one another. I wholeheartedly thank Moorfields Eye Hospital for hosting an event that enabled us to meet each other.’

To donate to Faye’s JustGiving page go to www.justgiving.com/FFai-x
To donate to Lisa’s JustGiving page go to www.justgiving.com/Lisa-McDonald06
should be treated like any other child. That is my view. If you tell her anything I would say that your daughter has a thyroid gland that doesn’t work properly and hence she is on thyroid hormone replacement which may mean that she misses the occasional half-day at school to have a check-up at the hospital. If she wants to know more then I am sure you can give her a tutorial or put her in touch with the BTF! You may also find it useful to look at the Children’s pages of the BTF website www.btf-thyroid.org/index.php/campaigns/children

Roisin Sharp who suffers from hypothyroidism and her dad ran the Mini Great North Run (1.5km) in September and have raised over £500! Three year old Theo who also suffers from hypothyroidism and his friend Maisie took part too and have raised an incredible £1,000!

Children’s Corner

If you are a young person with a thyroid disorder we would love to hear from you about your experiences of managing your condition and coping with any problems you may have had along the way. We know how invaluable it can be to read about other people’s experiences so please let us know how you feel about your thyroid, by sending in poems, stories or artwork – however you like to express yourself!

If you would like information or have a question you would like an answer to you can write in to Children’s Editor (BTF), Second Floor, 3 Devonshire Place, Harrogate HG1 4AA or email children@btf-thyroid.org. We will ask our children’s medical expert Dr Tim Cheetham to reply to you and publish the letter in the Children’s Corner. Don’t forget to ask your parents to sign the letter if you are under 18.

KY asks: I am writing to ask for advice after seeing your page on the BTF website. My daughter has congenital hypothyroidism (CHT) and will soon be starting school. My question is what should I be telling her teacher about her condition? I’m aware it will probably be something she’s not encountered before, so she should look out for anything in particular that could be attributed to her thyroid condition? She is a bright girl but I do find her behaviour challenging at times but haven’t known if this is just normal extended toddler behaviour or not. Thank you in advance for any advice you are able to offer

Dr Tim replies: It is a very personal matter but I am not sure the teacher really needs to know anything. Your daughter is a healthy child on thyroxine replacement – there are no acute/emergency health issues because of the underlying CHT and I suspect her behaviour has absolutely nothing to do with CHT. From the teacher’s perspective she is a healthy child who

BTF £20,000 Research Award 2015

The BTF offers an annual award to support one-year research projects into thyroid function or thyroid disorders. This year’s award is up to £20,000 and is specifically for research to improve our understanding of hypothyroidism.

Applications for this year’s award are invited specifically for research into assay and assessment of thyroid function with particular application into the diagnosis and management of hypothyroidism. The award can be used to supplement existing projects or to help get research ideas started. Funds will be awarded for consumables, running costs and equipment.

The British Thyroid Foundation is an NIHR partner organisation in respect of its research awards funding stream. Studies funded through this funding stream are eligible for inclusion in the NIHR Clinical Research Network Portfolio and therefore able to access NHS support via the NIHR Clinical Research Network infrastructure.

For further information and an application form, go to: www.btf-thyroid.org, email research-award@btf-thyroid.org or phone: 01423 709707. The closing date for receipt of applications is 31 January 2015.
Endocrinology, Royal Devon and Exeter Hospital for their proposal to study the pregnancy using management of hyperthyroidism during primary care cohort data from a large pregnancy; data from a large primary care database totalling over 17,000 people with hyperthyroidism to identify the risks and benefits of current practice and identify where management might be improved. They explain: ‘We will identify whether treatment targets are being routinely met and the degree of harm (such as miscarriage) arising from failure to achieve these. Furthermore we will be able to study for other adverse obstetric outcomes (e.g. need for emergency caesarean section) and adverse offspring outcomes (e.g. congenital abnormalities) by treatment adequacy and also for carbimazole and propylthiouracil. This will enable us to inform both patients and clinicians of best practice, for instance with regard to management of hyperthyroidism in pregnancy and reducing the risk of adverse outcomes. A key advantage of the nature of this research is that data have already been collected allowing rapid analysis of results as conventional studies would take years to acquire these data.’

Dr Taylor and Dr Vaidya added: ‘Once again thank you to the BTF for all your support, it is very much appreciated’.

Both Dr Taylor and Dr Vaidya have substantial expertise in analysing this database and have published several research studies relating to thyroid disorders in pregnancy.

Dr Peter Taylor, Welsh Clinical Academic Trainee at Cardiff University and Dr Bijay Vaidya, Consultant in General Medicine, Diabetes and Endocrinology, Royal Devon and Exeter Hospital for their proposal to study the management of hyperthyroidism during pregnancy using data from a large primary care cohort.

Here they explain their proposed research:

‘It is well known that abnormal thyroid function in women who are pregnant is associated with increased risk of miscarriage, problems with delivery and may impair offspring development. Whilst it is well established that pathological thyroid dysfunction is associated with adverse outcomes, we are now becoming aware that even minor variation in thyroid status within the normal population range has key health implications particularly in pregnancy.

‘Hyperthyroidism (thyroid overactivity), usually due to Graves’ disease, is a relatively common disorder in pregnancy, afflicting about 1 in 500 pregnant women. Data on whether hyperthyroidism in pregnancy is optimally managed in the UK and outcomes of the pregnancies associated with hyperthyroidism are lacking and studies have been relatively small in size to date. In particular there are concerns regarding the adequacy of current treatment in terms of control of thyroid status, with subsequent increased risk of adverse pregnancy outcomes including miscarriage and need for an emergency Caesarean section. Furthermore there is concern over which anti-thyroid drug is safest to use in pregnancy. Current guidelines recommend propylthiouracil as the preferred antithyroid drug in early pregnancy as carbimazole is associated with congenital abnormalities. However recent data has led to concerns over propylthiouracil use as it can cause liver failure and its use has now also been associated with congenital abnormalities. The guidelines have suggested that using propylthiouracil in the first trimester and switching over to carbimazole afterwards might provide the lowest risk of adverse outcomes, however this has not been studied and there are concerns regarding whether this switch results in a deterioration of hyperthyroidism. Taken together there is a pressing need to examine this important topic and identify where current management could be improved.’

Dr Taylor and Dr Vaidya propose to analyse a large primary care database totalling over 17,000 people with hyperthyroidism to identify the risks and benefits of current practice and identify where management might be improved. They explain: ‘We will identify whether treatment targets are being routinely met and the degree of harm (such as miscarriage) arising from failure to achieve these. Furthermore we will be able to study for other adverse obstetric outcomes (e.g. need for emergency caesarean section) and adverse offspring outcomes (e.g. congenital abnormalities) by treatment adequacy and also for carbimazole and propylthiouracil. This will enable us to inform both patients and clinicians of best practice, for instance with regard to management of hyperthyroidism in pregnancy and reducing the risk of adverse outcomes. A key advantage of the nature of this research is that data have already been collected allowing rapid analysis of results as conventional studies would take years to acquire these data.’

Dr Taylor and Dr Vaidya added: ‘Once again thank you to the BTF for all your support, it is very much appreciated’.

Both Dr Taylor and Dr Vaidya have substantial expertise in analysing this database and have published several research studies relating to thyroid disorders in pregnancy.

Evelyn Ashley Nurse Award winner 2014

The winner of the 2014 Evelyn Ashley Nurse Award of £500 is Greta Lyons, Endocrine Research Nurse, Clinical Research Facility, Addenbrookes Hospital, Cambridge.

Greta works in a multi-disciplinary team that investigates and manages patients with rare and unusual disorders of thyroid hormone action including Resistance to Thyroid Hormone (RTH). The team receives referrals of cases from centres throughout the UK and internationally. In addition to looking after patients when they come to the Clinical Research Facility in Cambridge, she also visits them in other hospital environments or at home, which allows families and patients flexibility, particularly if they are unable to travel great distances. This also enables equity of patient access to the rare thyroid disorder service at Addenbrooke’s Hospital in Cambridge. Another aspect of Greta’s role is as patients’ advocate ensuring they and their families are well supported throughout the clinical investigation and research process.

RTHbeta is a dominantly-inherited disorder, characterised by elevated thyroid hormones, with non-suppressed TSH levels, due to defects in the thyroid hormone receptor beta gene. Features in childhood can include failure to thrive and attention deficit hyperactivity disorder; adults with this disorder can have features of both hyperthyroidism and hypothyroidism. Recently, the first patients with RTHalpha and defects in the thyroid receptor alpha gene have been identified. Features include growth and developmental retardation in childhood, but associated with subtle alteration in thyroid function. The contrasting features of RTHbeta and RTHalpha indicate different treatment and monitoring for the two disorders.

The award has given Greta the opportunity to attend a Paediatric Endocrine Course next year. This will allow Greta the chance to influence and strengthen the nursing and clinical care for patients and continue to work collaboratively with colleagues in all settings, nationally and internationally.

Greta says: ‘I am extremely grateful for the support from the BTF and the Evelyn Ashley Nurse Award Committee.’

Greta Lyons

Greta Lyons, Research Nurse, Clinical Research Facility, Addenbrookes Hospital, Cambridge.
Smith award to give me this opportunity to attend this course as although I have over twenty five years’ experience of working with children and their families, both in the hospital and community, this course will develop my skills and abilities within this rare thyroid client group. I consider this course a springboard for personal development and learning but also an invaluable opportunity to explore themes for the care of patients with Resistance to Thyroid Hormone; in particular I wish to develop information leaflets for patients and families with these disorders’.

Evelyn Ashley Nurse Award winner 2012 - final update

Thyroid Eye Disease (TED) and its management and DVD Audit

Nicola Dunlop, Advanced Nurse Specialist at Moorfields Eye Hospital, London has sent us the following report on her audit of the TED DVD:

The BTF played an instrumental part in the making of the ‘Thyroid Eye Disease and its Management’ DVD and present audit. The audit methodology was to capture data from patients recently diagnosed with thyroid eye disease or from patients about to embark on a new aspect of care, for example a patient successfully medically managed and now about to undergo decompression surgery (an operation that removes one or more of the bony eye socket walls creating space to set the protruding eye back into the eye socket). All patients were given a questionnaire containing 10 questions to complete and return immediately at the time of their clinic visit. Along with the thyroid eye disease DVD a second questionnaire with 12 questions were given to patients. They were expected to return the second questionnaire at their next clinic appointment or in the case where the patient’s next appointment might be longer than two months it was advised that the questionnaire be returned via the post. The data collected and analysed so far came from a total of 77 questionnaires that were immediately filled in and 29 questionnaires returned after viewing the DVD. There is overwhelming evidence so far to indicate that the DVD has indeed acted as a teaching tool. Before viewing the DVD all patients were asked, ‘Do you think a DVD would provide useful information on thyroid eye disease?’ Fourteen patients responded ‘they did not know’, eight patients said ‘to some extent’ and a total of 55 stated ‘yes’. 100% of patients who returned the second questionnaire stated, ‘yes’, that they had more knowledge of the condition after viewing the DVD.

Another conclusive finding that indicates that the DVD has indeed provided greater understanding of the condition was found in the answer to the question, ‘Do you think you have a better understanding of thyroid eye disease having watched the DVD? From the options; ‘no’, ‘yes’ and ‘to some extent’, none of the patients stated ‘no’, 83% stated ‘yes’ and 17% stated ‘to some extent’. One important take-home for patients who viewed the DVD was that smoking has an adverse effect on thyroid eye disease and that message was well understood as 100% of patients who returned the questionnaire from the options ‘don’t know’, ‘makes it better’ or ‘makes it worse’ all chose ‘makes it worse’. Nicola says: ‘I am extremely grateful to the BTF for making this audit possible and look forward to further analysing all the data received as the audit progresses, as well as presenting it at the Allied Professional Study Day in Manchester on 18 October 2014. The making of the DVD and its audit proposal was presented at the Clinical Pharmacy Congress on 26 April 2014, thanks to the BTF’.

Nicola took part in the recent Fight for Sight Carrot NightWalk around London and raised almost £450, see page 3.

Fight for Sight/British Thyroid Foundation Small Grant Award winner 2014

Mr Daniel Ezra

is Mr Daniel Ezra, Consultant Ophthalmologist at Moorfields Eye Hospital and lecturer at the UCL Institute of Ophthalmology. Here he explains his research study on Application of 3D facial imaging system in the management of Thyroid Eye Disease:

Thyroid Eye Disease (TED) is a condition in which the immune system attacks tissues surrounding the eyes, producing inflammation and swelling. Double vision, protruding eyes, discomfort, redness and reduced vision are common features. The disease is variable and can have both blinding and immense psychosocial consequences.

Disfigurement is a particular burden to TED patients and there are currently limited ways of measuring this.

The Vectra M3 3D imaging system (Canfield Imaging, Fairfield, NJ, USA) is a sophisticated tool that has been used in the fields of reconstructive breast and facial surgery as well as cosmetic surgery. This system can capture 3D images of patients to enable more accurate measurement of changes in contour and shape. This could be an invaluable way detecting progression of disease and response to treatment and could also help doctors to measure the effect of different treatments and compare new with existing treatments to decide which is better. The system can also act as a simulator to show predicted changes which could help patients understand the potential benefits in appearance which surgical treatment can bring. No systematic work to investigate the use of this system has ever been performed in TED patients. Our research aims to help answer the question: Is the Vectra M3 3D imaging system a useful and reliable tool for managing TED?

We aim to conduct a series of studies to investigate this system. Firstly, a study to image TED patients before and after surgical treatment aimed at reducing ‘protrusion’ of the eyes. Secondly, a study to assess TED patients during the course of their disease to analyse how good 3D imaging is compared to the tools/measures of disease that doctors already use. Thirdly, a study to investigate the effect of eye drops on reducing eye protrusion, which has been suggested by several laboratory studies.

This work could help bridge the gap in research exploring measures of appearance in disfiguring orbital diseases and the results could therefore be far-reaching and relevant for doctors and patients.

Mr Ezra added: ‘I am delighted to win this award and am very grateful to the BTF and the FFS for making it possible to conduct this important research’.
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, 3 Devonshire Place, Harrogate, North Yorkshire HG1 4AA or by email to editorialboard@btf-thyroid.org

Please address medical queries to the Medical Enquiries Coordinator at the address above or by email to medical-query@btf-thyroid.org

Please remember to include your membership number.

Unless you state otherwise, we will assume that you consent to having your letter and reply published in the newsletter. Medical queries will be anonymised.

Medical questions, whether or not intended for publication, will normally be referred to one of our medical advisors, and you will receive a confidential reply. Please note that our advisors are not able to give you a written personal consultation and that their advice is provided for information only. For specific medical queries 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.

Radioactive iodine treatment precautions

**JF asks:** I have the following questions regarding radioactive iodine treatment (RAI) for my hyperthyroidism and would be grateful if you could pass these on to somebody that I have very little Graves’ eye disease and would therefore be able to have RAI.

1. Can the severity of Graves’ eye disease be determined just by looking at a patient, therefore deciding whether or not having RAI treatment would be a suitable form of treatment? (I have been told by my consultant that I have very little Graves’ eye disease and would therefore be able to have RAI.)

2. Would it be safe enough to just keep my distance from my boyfriend and cat at home for a few weeks or should I look at staying somewhere else, during that time?

3. Would I need to take time away from work or from home? My work is office-/computer-based.

**Our medical advisor replies:**

(1) Most endocrinologists will avoid radioiodine in patients with thyroid eye disease, which in most cases can be excluded by a simple physical examination of the eyes.

(2) Following radioiodine, patients should avoid prolonged intimate contact with their partners since radioactivity from patients may be transmitted to close contacts. It is OK for the patient to stay in the same house with the cat and boyfriend provided close continuous intimate contact is avoided.

(3) If the patient works in an office where there are other co-workers within a confined space then it is advisable to take two weeks off work to reduce the risk of exposing co-workers to radioactivity.

It is important, however, to note that the endocrinologist attending to the patient is best placed to decide on whether radioiodine is appropriate. The clinician or the radioiodine therapist will provide information on the precautions to be taken after radioiodine treatment and can answer specific queries that may arise.

Concerns about a reduction in dose of levothyroxine

**CF asks:** I have been on levothyroxine for the last 10 years and have been on 150mcg for the last three years or so. As a result of my last blood test I have been informed that the doctor wants to reduce my thyroxine to 125mcg. My results were TSH 0.09 and FT4 22.9. I understand why they are thinking of reducing my medication because of these results, but I don’t have much faith in doctors on such things, being aware that they don’t tend to understand the condition well. I have been feeling OK on 150mcg so I am concerned about how I might feel on the lower dose. I always have a fast heartbeat but doctors have never been concerned about that before and I haven’t been told that this is connected with the decision. Isn’t it unusual to have medication reduced? Could the fact I have been taking a strong probiotic (Symprove) for my diverticulitis affect the results? Do you think I should try the 125mcg for a bit or not?

**Our medical advisor replies:** Strictly speaking, you are slightly overtreated, and that is why they are thinking about the dose reduction. If you are concerned about it, I would negotiate a reduction to 150mcg four days weekly and 125mcg on three days weekly. This may be a good compromise and remember that on the day when you get a blood recheck, don’t take your levothyroxine until after your blood test, as this is the common reason for a slightly high FT4.

If you don’t feel as well after a month or two on the 150/125mcg dose, then you can always go back and discuss it.

Is this a thyroid problem?

**JP asks:** I have recently had a scan on my thyroid and seen an endocrinologist who said that I have a 2mm nodule on my thyroid. I am suffering from heat intolerance to the point that I have to be under or in front of a fan day and night! My GP sent off for TSH and said it was normal. My daughter has an undetectable thyroid and I have CFS/fibromyalgia. I have been on Tapentadol for 18 months now. I am 55 and post menopause I think, as I have had no periods for two years. My temperature is low - between 35.6 and 36.6. As soon as I do anything I am sweating all over and my hair is wet. Do you think I should see another doctor? I am due to go on holiday in a month and don’t think I will be able to tolerate the heat as it makes me feel shaky, giddy and faint. I would really appreciate any help you can offer.

**Our medical advisor replies:** A 2mm nodule is something that is very commonly seen on an ultra sound scan and is not something he would be concerned about. If your TSH is normal then I suspect that the thyroid is not the cause of your symptoms. I suggest that you speak to your GP about these symptoms to see if there might be another explanation.

Progesterone levels and the thyroid

**JV asks:** How often does Graves’ disease affect progesterone levels? My progesterone levels remained normal so my gynaecologist told me they assumed I did not have a thyroid problem. Would you expect a gynaecologist to recognise a goitre? Would you expect a GP or gynaecologist to know that 30% of people with vitiligo have a thyroid condition (NICE guidelines)?

**Our medical advisor replies:** There is no direct evidence that Graves’ disease or hyperthyroidism affects progesterone concentrations. High progesterone levels have been found in hyperthyroid men with
Graves’ disease in one study. The effects of hyperthyroidism on fertility are mainly related to high levels of circulating thyroid hormones resulting in an increased miscarriage risk. In order to identify Graves’ hyperthyroidism, thyroid function tests and thyroid antibodies would need to be measured. Examination of the neck is not part of a routine gynaecological evaluation and unless the goitre was clearly visible I would not expect a gynaecologist to detect this. I would expect a GP or gynaecologist to know that autoimmune diseases go together and that patients with an autoimmune condition are at risk of getting another autoimmune condition including thyroid disorders. I would not necessarily expect them to know the exact figures quoted in the NICE guidelines.

How useful are radioisotope scans to detect thyroid cancer?

J asks: For diagnostic purposes, to see whether a large nodule is cancerous or benign, is it possible to do a radioisotope scan to show one or the other or the likelihood, or must it be surgery to take away half the thyroid so that it can be analysed?

I am not keen on losing half my thyroid, even if one can function with half, for simply diagnostic purposes if it is possible to do it another way. I had an ultrasound scan and biopsy, which showed one large nodule a bit different from the rest, with the biopsy diagnosing follicular lesions but not clearly cancer.

Having lived in Paris for a long time in the past and having gone with a friend to the Institut Curie, I looked at their website and both they and other websites say that this test is used to diagnose and well as using a larger dose to treat post-op cancer thyroid patients.

Our medical advisor replies: This is unfortunately a common and difficult problem. The background to the isotope scan is that some years ago, when the function of the thyroid gland through blood tests was not as sensitive or precise as now, isotope scans were used frequently in the UK. The basis for this is that nodules that take up radioiodine and are therefore ‘functional’ are unlikely to be cancerous. Now that thyroid blood tests are so much better, we can classify glands as being functional or not on the basis of the blood test with a very high degree of accuracy. That means that the iodine scan adds little more value. This is the stance that British guidelines have taken based on the available evidence. However, other countries have differing views, so in the USA isotope scans are still being used and perhaps also in France. It is worth highlighting that even when the isotope scan shows uptake (ie low risk of cancer) it does not definitely exclude cancer, the probability of scan positive nodules being cancerous have been variously reported to be between 1-10%.

Ultimately the level of suspicion for thyroid cancer needs to take into account a number of clinical parameters (like patient age, family history of thyroid cancer, previous exposure to radiation), the appearances of the ultrasound (here the experience of the operator is crucial, but among all the various assessments for potential thyroid malignancy, the ultrasound characteristics outweigh all others), and the biopsy result.

Most cytopathologists subclassify the type of follicular results into Thy3a and Thy3f. Most thyroid experts will recommend repeat biopsy and surveillance with Thy3a results and diagnostic hemithyroidectomy for Thy3f, because of the odds of thyroid cancer associated with these two types.

Some new diagnostic tests (molecular markers) have been developed, that can be applied on the biopsy specimens, which look promising. In the US, they have been commercialised and are being offered, but they are very costly. They are not available on the NHS and UK experts feel that they have not been validated sufficiently yet to be applied with confidence in clinical practice. I hope this is helpful.

Feeling unwell after restarting levothyroxine

ST asks: My son has had an under-active thyroid since he was a young boy. He is 19 now, and he’s not been taking his levothyroxine tablets for months... with obvious side effects. He has now acknowledged that he should be taking his tablets and has started on a low dosage but seems to be feeling ill from taking the tablets (which is why he stopped taking them in the first place). Is he doing the right thing just starting up again and should he just ride it out until his body gets used to the tablets?

Our medical advisor replies: I suggest he makes an appointment to see his GP to explain what has happened so that they can monitor him carefully until he gets back to the right dose again. Encourage him to discuss the symptoms or side effects he was having before he stopped the tablets (and that he’s having again now). It may be that the problem was that he wasn’t getting the right dose at that time. The amount of thyroxine we need does fluctuate from time to time which is why it’s important to have regular blood tests.

<0.1 TSH with hypothyroidism

SM asks: I am a 66 year old female who has been treated successfully for hypothyroidism for approximately 25 years. However, my TSH has always been <0.1. I had thought that my pituitary gland would have been trying to stimulate my thyroid and consequently this level should be higher?

Our medical advisor replies: The hormone TSH is produced by the pituitary gland. Patients with an untreated under-active thyroid gland have a high TSH as the TSH tries to stimulate the thyroid gland. However, in patients on thyroxine, a low TSH level is due to the drug which sends signals to the pituitary to reduce its production of TSH. This is known as the negative feedback effect and suggests that the thyroxine dose is excessive. Some clinicians may lower the thyroxine dose when TSH is low while others will leave the dose unchanged if the patient feels well. Ultimately the decision rests with your clinician.

Finding a NHS or Private Surgeon

JB asks: I have been told I require a thyroid lobectomy to remove a 2.5cm nodule, can you let me know the best surgeon in East Anglia please?

Our Reply: We regret that we are unable to recommend specialist and clinics, but it is important that you find an experienced surgeon.

NHS Choices have a website that may provide the details of surgeons in the location of your choice: www.nhs.uk/Service-Search/Hospital/LocationSearch/B/Consultants. The menu allows you to search by speciality (endocrinology) and location, or by the consultant’s name. You may wish to telephone the specialist’s secretary to explore how experienced they are.

There are a number of websites giving contact details of private specialists, such as: www.privatehealth.co.uk/private-hospitals/hospitaltreatment-findahospital/www/consultant-search.co.uk/ www.finder.bupa.co.uk/ www.finder.bupa.co.uk/ www.doctoralia.co.uk/ www.finder.bupa.co.uk/ www.doctoralia.co.uk/ Please note we have not assessed the quality and accuracy of contact information from any of these websites.
In The Media

Thyroid cancer awareness month

September was Thyroid Cancer Awareness Month and one of our partner organisations, Butterfly Thyroid Cancer Trust, organised various ‘Neck Check’ events at local hospitals where experts were on hand to carry out free neck checks and to talk with visitors. The event was featured on Tyne Tees TV.

Metformin link with underactive thyroid

The Daily Mail reported on 22 September 2014 that research published in the Canadian Medical Association Journal found a link between Metformin, a drug widely prescribed to those with type 2 diabetes, and an underactive thyroid. The study warned there is an increased risk of producing low levels of the thyroid-stimulating hormone (TSH).

Professor Mark Strachan, a BTF Trustee, commented: ‘The authors have made an interesting observation but as they say themselves further research is needed to determine if this is a clinically important effect. In the meantime, it would be reasonable to recommend that patients with treated hypothyroidism should have their thyroid function tests checked several weeks after starting on Metformin’.

Iodine deficiency in pregnant women

The Daily Mail published an article on 19 September 2014 entitled ‘Maths skills decided in the womb’ that featured comments from Professor John Lazarus, former BTF trustee, and Chair of the UK Iodine Group.

The article was concerning recent research by scientists at the VU University Medical Centre in Amsterdam, which showed that children born to mothers who have low levels of thyroid hormones during pregnancy tend to do worse in maths in early primary school. The Dutch researchers tracked 1,196 healthy children from birth to age five, having recorded their mothers’ thyroid hormone levels at 12 weeks of pregnancy.

They then looked at the children’s test scores for language and arithmetic. Those born to mothers with low levels of thyroxine were twice as likely to have below-average arithmetic scores but no difference was seen in their language results, even after taking into consideration the child’s family background.

Professor Lazarus explained in the article that this widespread problem is due to a lack of iodine in the diet. Unborn babies are unable to produce their own thyroxine and have to rely on their mother’s supply. Pregnant women therefore need to ensure they have enough iodine in their diet. He said studies have shown that up to two thirds of pregnant women in Britain were or are low in iodine and recommended that iodine should be added to salt to boost consumption – a move taken by other countries.

Professor Lazarus also advised that it is safe for pregnant women to take 100 to 150 micrograms of iodine a day as a supplement.

Medicines Update

New thyroid cancer drug

Eisai, a Japanese drug company has recently filed an application to the European Medicines Agency (EMA) for the use of a new drug called Levantinib to treat thyroid cancer. (See page 4)

Crumbling tablets

Following a letter by Peter Foley (former BTF Trustee) in BTF News 86 (p.14) on the problem of crumbling Actavis tablets we have spoken to Actavis who expressed concern at this issue. They have asked anyone who has experienced a problem to contact them on 01271 385257 or email medifo@actavis.co.uk

Drug interactions with levothyroxine

A study to determine the extent of drug interactions affecting levothyroxine has discovered that some drugs significantly reduce the effectiveness of levothyroxine: iron, calcium, proton pump inhibitors and oestrogen all increased serum TSH concentration. The study population was 10,999 Tayside residents prescribed levothyroxine on at least three occasions, within a six month period, prior to the start of a study drug. The study found that iron, calcium, proton pump inhibitors, and oestrogen all increased serum TSH concentration whilst there was a decrease in the TSH concentration for patients on statins. There was no effect with H2 receptor antagonists or glucocorticoids.

The study recommends that patients on these combinations of drugs should be carefully monitored due to potential of a reduction in effectiveness of levothyroxine.

More on the study can be found at: www.ncbi.nlm.nih.gov/pubmed/25040647

Source: Jul 17 2014 Clinical Endocrinology.
Local Groups

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

Belfast

Next meeting: The group meets every two months - please contact Ursula for the next meeting date or visit the BTF website - all welcome!

Location: Merchant Hotel, Belfast (High Street entrance).

Contact: Ursula Tel: 07720 659849 or email: ursulajordan06@aol.com

Birmingham

Next meeting: Check the BTF website for details.

Donation: £2 voluntary donation for venue costs and refreshments.

Contact: Janet Tel: 0121 628 7435 or email: janetdmp@googlemail.com

Cambridge

Next meeting: Check the BTF website for details.

Donation: Suggested minimum donation: £3

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

Edinburgh

Next meeting: The Edinburgh BTF Support Group meets on the last Tuesday of the month except for school holidays.

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

This meeting is a ‘drop-in session’ and anyone is welcome between 7.15pm and 8.30pm to discuss their particular thyroid condition and to get advice and support. Check the BTF website for further details.

Contact: Margaret Tel: 0131 664 7223 or email: M2mcgregor@aol.com

Leeds (Wharfedale)

Next meeting: Come along for an informal meeting on Wednesday 26 November at 7.30pm to meet and chat with others on all matters and side effects of thyroid problems.

Location: Caroline’s house in Leeds 21 (five minutes from Harewood House)

Donation: No charge but a small donation to the BTF would be appreciated.

Contact: Caroline Tel: 0113 288 6393 or email: cfields237@btinternet.com for more information.

London

Next meeting: TBA - check the BTF website for details.

Donation: Suggested minimum £3 donation

Contact: Denise Tel: 07984 145343 or email: denisesims@btf-thyroid.org

Milton Keynes

Next meeting: Information event on Saturday 7 March 2015 10.30am.

Information events are held at 10.30am every three months. Check the BTF website for further details.

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

Donation: £2 voluntary donation for room hire and expenses of running the group.

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

Notts/Derby

Next meeting: 1 December 2015 from 7pm to 8.30pm. The group will now meet every three months instead of monthly (excluding bank holidays). Check the BTF website for details.

Location: The Staff of Life public house, West End, Sutton-in-Ashfield, Notts, NG17 1FB

Contact: Bridget Tel: 01623 750330 after 6pm on weekdays and anytime at weekends.

Fundraise for us!

Check out the different ways our supporters raise money for us on page 5 and 6

Leaving a legacy to the BTF

Legacies are a vital source of income for our work – important campaigns and projects - and enable us to continue funding research projects into thyroid disorders that is so urgently needed: the BTF Research Award of £20,000 and the Endocrine Nurse award that we offer annually has been funded by a legacy of £108,000 left to us by long-standing member Evelyn Ashley Smith. If you would like an information leaflet on leaving a gift in your will please call our office on 01423 709707 or email julia.priestley@btf-thyroid.org
## BTF Local Coordinators

Our local coordinators organise meetings but will also be happy to take calls on thyroid disorders that they have experienced. Please see the key below.

<table>
<thead>
<tr>
<th>City</th>
<th>Coordinator</th>
<th>Telephone</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belfast</td>
<td>Ursula</td>
<td>07720 659849</td>
<td><a href="mailto:ursulajordan06@aol.com">ursulajordan06@aol.com</a></td>
</tr>
<tr>
<td>Birmingham</td>
<td>Janet (PC,CS,RAI,PH)</td>
<td>0121 6287435</td>
<td><a href="mailto:janetdmp@googlemail.com">janetdmp@googlemail.com</a></td>
</tr>
<tr>
<td>Cambridge</td>
<td>Mary (O,RI,U)</td>
<td>01223 290263</td>
<td><a href="mailto:butterflyecho@hotmail.com">butterflyecho@hotmail.com</a></td>
</tr>
<tr>
<td>Edinburgh</td>
<td>Margaret (PC)</td>
<td>0131 6647223</td>
<td></td>
</tr>
<tr>
<td>Leeds (Wharfedale)</td>
<td>Caroline (O,U)</td>
<td>01132 886393</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td>Denise (U)</td>
<td>07984 145343</td>
<td><a href="mailto:denisesims@btf-thyroid.org">denisesims@btf-thyroid.org</a></td>
</tr>
<tr>
<td>Milton Keynes</td>
<td>Wilma (U)</td>
<td>01908 330290</td>
<td></td>
</tr>
<tr>
<td>Notts/Derby</td>
<td>Bridget (GR,TS,U,PH)</td>
<td>01623 750330</td>
<td></td>
</tr>
</tbody>
</table>

### BTF Telephone Support Contacts

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

<table>
<thead>
<tr>
<th>City</th>
<th>Contact</th>
<th>Telephone</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belfast</td>
<td>Ursula</td>
<td>07720 659849</td>
<td><a href="mailto:ursulajordan06@aol.com">ursulajordan06@aol.com</a></td>
</tr>
<tr>
<td>Birmingham</td>
<td>Janet</td>
<td>0121 6287435</td>
<td><a href="mailto:janetdmp@googlemail.com">janetdmp@googlemail.com</a></td>
</tr>
<tr>
<td>Cambridge</td>
<td>Mary</td>
<td>01223 290263</td>
<td><a href="mailto:butterflyecho@hotmail.com">butterflyecho@hotmail.com</a></td>
</tr>
<tr>
<td>Edinburgh</td>
<td>Margaret</td>
<td>0131 6647223</td>
<td></td>
</tr>
<tr>
<td>Leeds (Wharfedale)</td>
<td>Caroline</td>
<td>01132 886393</td>
<td></td>
</tr>
<tr>
<td>London</td>
<td>Denise</td>
<td>07984 145343</td>
<td><a href="mailto:denisesims@btf-thyroid.org">denisesims@btf-thyroid.org</a></td>
</tr>
<tr>
<td>Milton Keynes</td>
<td>Wilma</td>
<td>01908 330290</td>
<td></td>
</tr>
<tr>
<td>Notts/Derby</td>
<td>Bridget</td>
<td>01623 750330</td>
<td></td>
</tr>
</tbody>
</table>

### Key

- **Ch**: Thyroid disorders in children
- **C**: Cancer of the thyroid
- **FC**: Follicular cancer of the thyroid
- **PC**: Papillary cancer of the thyroid
- **HCN**: Hürthle Cell Neoplasm
- **CS**: Thyroid cancer surgery
- **RAI**: Radioactive iodine (I-131) ablation
- **G**: Goitre
- **TS**: Thyroid Surgery (non-cancer)
- **U**: Under-active thyroid
- **ITSH**: Isolated TSH deficiency
- **O**: Over-active thyroid
- **GR**: Graves’ disease
- **RI**: Radioactive iodine treatment for an over-active thyroid
- **TED**: Thyroid eye disease
- **PH**: Post-operative hypoparathyroidism

### Our Partner Organisations

- **AMYEND**: Tel: 01892 516076 [www.amend.org.uk](http://www.amend.org.uk)
- **Hypopara (HPTH) UK**: [www.hypopara.org.uk](http://www.hypopara.org.uk)
- **Butterfly Thyroid Cancer Trust**: Tel: 01207 545469 [www.butterfly.org.uk](http://www.butterfly.org.uk)
- **Thyroid Eye Disease Charitable Trust**: Tel: 0844 8008133 [www.tedct.org.uk](http://www.tedct.org.uk)
- **British Thyroid Association**: [www.british-thyroid-association.org](http://www.british-thyroid-association.org)
- **British Association of Endocrine and Thyroid Surgeons**: [www.baets.org.uk](http://www.baets.org.uk)

### Current Membership Rates

<table>
<thead>
<tr>
<th>Category</th>
<th>By Cheque</th>
<th>By Standing Order</th>
<th>Lifetime Membership</th>
</tr>
</thead>
<tbody>
<tr>
<td>Members living in the UK</td>
<td>Full: £20 per year</td>
<td>Full: £17 per year</td>
<td>£200 by cheque</td>
</tr>
<tr>
<td></td>
<td>Concession: £10 per year</td>
<td>Concession: £8.50 per year</td>
<td></td>
</tr>
<tr>
<td>Members living overseas</td>
<td>By cheque from a UK bank account</td>
<td>By standing order through a UK Bank</td>
<td></td>
</tr>
<tr>
<td>£25 Europe</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>£35 Outside Europe</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Concession: unwaged, senior citizen (over 65), under-18s and students in full-time education. Please help us by ensuring that you pay the correct subscription.

### Order your BTF Christmas Cards

We have a great collection of contemporary and traditional Christmas cards that we are selling to raise funds for the BTF. We would be very grateful for your support.

You can order your cards now by filling in the flyer enclosed with this newsletter or by visiting the BTF website: [www.btf-thyroid.org](http://www.btf-thyroid.org), where you can pay with credit or debit card. Cheques should be made payable to the British Thyroid Foundation.