BTF LAUNCHES INITIATIVE TO IMPROVE CARE OF HYPOTHYROIDISM

As reported in BTF News issue 84 (October 2013) the British Thyroid Foundation intends to put the issue of hypothyroidism in the foreground of its activities by launching a patient-led hypothyroidism care initiative.

In December, representatives of the BTF met with the Executive Committee of the British Thyroid Association (BTA), the organisation representing thyroid researchers and specialists, to present a draft plan.

The intended outcomes of the plan for patients with hypothyroidism are: the availability of better information in GP surgeries and consulting rooms; a better understanding of their disorder; a better relationship with their doctor involving more satisfactory medical consultations leading to better recognition and effective treatment of persistent symptoms; the need for fewer repeat visits to GPs; and more consistency in treatment with reliable formulations of levothyroxine.

The intended outcomes for GPs, medical and healthcare professionals are: better informed patients through access to targeted BTF information and support; fewer repeat visits by hypothyroid patients with persistent symptoms; greater confidence in the consistency of levothyroxine prescribed and better understanding of issues of brand versus generic prescribing; and more effective treatment of hypothyroid patients with better long term outcomes.

Janis Hickey, BTF Director, says: ‘We have been listening to hypothyroid patients and recognise the need to improve communication between patients and their healthcare professionals, including GPs, nurses and pharmacists. This year we intend to put hypothyroidism in the foreground and have asked Vivienne Rivis, who is a BTF volunteer, to develop the strategy and to help to implement it.’

Vivienne Rivis explains: ‘Initial feedback to our ideas from our various consultations with GPs and discussions with the BTA have been positive. Both the GPs and the BTA have given us valuable suggestions.

‘Overall, the message has been supportive, with the BTA happy to be involved in developing work with GPs and patients to provide guidelines on managing the care of those with ongoing symptoms.

‘It has been suggested that new guidelines for GPs on hypothyroidism care would be welcomed, especially if linked to continuing professional development.’

Thyroid Awareness Week 25-31 May 2014

International Thyroid Awareness Week (ITAW) takes place every year in May. It is an initiative of the Thyroid Federation International (TFI) and is endorsed by the European Thyroid Association (ETA), the American Thyroid Association (ATA), the Latin-American Thyroid Society (LATS), the Chinese Society of Endocrinology (CSE) and the Chinese Society of Nuclear Medicine (CSNM).

This year’s ITAW will focus on ‘Five reasons to be aware of thyroid disease: thyroid cancer, autoimmune disease, infertility, anxiety/depression, and iodine deficiency’.

Keep an eye on our website for more information.
Letter from BTF HQ

Many thanks for all your Christmas cards and support over the past year. I would like to take this opportunity to thank everyone who has raised funds, donated money and given their time throughout the year.

2013 was an important and memorable year for the BTF in many ways. We celebrated our 21st anniversary - a milestone that has given us a chance to reflect on the enormous changes that have happened in patient care and support since we started. It is encouraging how many invitations we now receive from health professionals to participate in studies and projects that are intended to benefit patients.

Over the years fundraising has become more and more important to us. In fact we had a record-breaking year in 2013, with an incredible £22,000 raised for us. We also staged our own fundraising concert in March to celebrate our anniversary and actively took part alongside other fundraisers in a sponsored night walk around London in September where we raised over £6,000 for thyroid eye disease research.

Fundraising, donations and legacies have enabled us to increase the amount we give to vital research into thyroid disorders, and that is all thanks to help from our members and many others. Our annual Research Award Grant was increased last year from £10,000 to £20,000, giving once again the opportunity to support much-needed research into thyroid disorders (see page 8). We were also able to fund a new research grant of £15,000 jointly with Fight for Sight and Thyroid Eye Disease Charitable Trust (TEDct), (see page 5).

We welcomed a new BTF Patron last year: Josef Craig who swam to gold in the 2012 Paralympic Games and who was diagnosed with Graves’ disease in 2011.

We have continued to make progress with our campaigns and special projects (children, cancer, pregnancy, iodine, and thyroid eye disease):

● We produced a child-friendly DVD on thyroid disorders and we are planning a children’s conference in April;

● An updated thyroid cancer booklet is due out in 2014;

● Our campaign to ensure adequate iodine intake in pregnancy is progressing (see page 11);

● We also plan to complete our thyroid eye disease project this year and produce a comprehensive report on our findings.

The final weeks of 2013 also saw the launch of a major new hypothyroidism care strategy focused on improving communication between hypothyroidism patients and their healthcare professionals, (see lead story).

None of this would be possible without the help of our volunteers, both at the office and further afield, the local coordinators and telephone contacts who provide support, the members’ panel who provide important feedback on our projects, and our Trustees and Patrons.

Thank you also for your continued support as members over the years. We hope you find our newsletter informative. We always like to hear of any suggestions you may have to improve it.

Finally, there are many different ways you can support us in 2014:

Leave a donation to us in your Will. In recent years legacies have been one of the most important sources of income to us. You can find more information in the legacy leaflet we have included in this newsletter.

Fundraise for us. Organise your own event and we will send you sponsorship material and publicise your event on our website. You could also join us on the annual ‘Carrots Nightwalk’ – a night time walk around several cities raising money for Thyroid Eye Disease (see page 3) or sign up for the London 10K run or our new ‘Big Summer Jaunt’ (see page 4).

Best wishes to you all for 2014.

Janis Hickey
Director, BTF
j.l.hickey@btf-thyroid.org

NEWS ABOUT BTF

Newsletter schedule

As you may have noticed this newsletter has been published a few weeks later this year as we have decided to move production to fit in with other projects. The next newsletter is scheduled to be published in July.

Welcome to...

Nikki Keiffer who has joined us as a Trustee. Nikki is a specialist endocrine nurse based at Leicester Royal Infirmary and won the BTF Evelyn Ashley Nurse Award in 2010 for her studies on thyroxine replacement in pregnancy and pre-conception.

Bev Le Brocq who has joined BTF HQ as an employee. Bev will be helping out with administration and finance in the office. She is an experienced administrator and previously worked for Harrogate Borough Council in their Finance Department and as part of a project management team for the AQA Examination Board. Originally from Scarborough, Bev moved to Harrogate in 1989 after a career break in Cyprus where she raised her family.

Liz Clegg, who works part time at BTF HQ and has now become Assistant Editor of the BTF newsletter.

Congratulations to...

Eleanor Temple, former BTF Trustee, who has had a baby boy called Hesdin.

Kate Farnell, Founder and CEO of our sister organisation the Butterfly Thyroid Cancer Trust, who was awarded an MBE for services to thyroid cancer research and thyroid cancer sufferers’ in the New Year Honours List.
Farewell to …

Jennifer Linley who has stepped down as BTF Trustee and Treasurer due to other commitments. Jennifer has played a key role in organising the accounting system and has worked for the BTF since 2009.

David Fortune who has stepped down as BTF Trustee to devote more time to travelling, but will continue to volunteer in the BTF office as much as possible.

Nikki Brady and Eleanor Temple who have also stepped down as BTF Trustees due to work and other commitments. Nikki and Eleanor have told us they will continue to support the BTF’s work - we only have to ask! We’re grateful to all of them.

Thyroid films

Thank you for the great response we had about participating in our thyroid disorder films. We are now working closely with the film production company, and filming is due to start shortly.

A bunch of carrots...

The BTF and Thyroid Eye Disease Charitable Trust (TEDct) were invited to partner with Fight for Sight (FFS) in its annual ‘Carrots NightWalk’ last year. Many organisations participate in this event each year to raise funds for research into eye diseases.

Twenty-eight supporters of BTF set out on either the six- or 15-mile walk around London, Birmingham or Glasgow and succeeded in raising almost £4,500.

Janet Prentice, one of our Trustees, completed the Birmingham walk. She said: ‘With encouragement from the other walkers I completed the 15 miles in four hours 21 minutes which included two pit-stops. I did gain a few blisters on the night and had a lot of aches and pains over the following few days but it was worth it!’

Janis Hickey writes: ‘We at BTF HQ weren’t quite so speedy! Dressed in our magnificent carrot costumes made by our volunteer Helen at BTF HQ, we managed the 15-mile walk around London in about six hours (with three pit stops for carrot cake and carrot soup along the way laid on by FFS).

‘We were walking with friends and relatives, along with nearly 500 other ‘carrots’, and it was a fantastic night. The sights of London looked truly magnificent lit up. We were stopped a few times by revellers along the way who thought we were pumpkins/smurfs or members of Greenpeace, but generally a whole bunch of carrots walking about didn’t seem to cause too much surprise!

‘Dr Anna Rose (daughter of Mr Geoffrey Rose, BTF Trustee) with her mum Christine decided to do the walk around London ‘blind’ (without her glasses). Another supporter, Sue Elliot, who has been diagnosed with Graves’ disease with thyroid eye disease, decided to walk to support the BTF and TEDct in memory of her mother and her husband’s mother who both passed away this year.

Condolesences

We were very sad to learn from ex-Trustee and former Chair of the BTF Board of Trustees Carole Ingham of the death of her husband Ian in January. We would like to extend our deepest sympathies to Carole and family and express our thanks to Carole for requesting that donations be made to BTF in lieu of flowers.

Children’s Conference 2014

Plans are now well under way for the BTF Children’s Conference that will take place in Leeds on Saturday 26 April 2014.

The aim of the meeting is to provide information for children with thyroid disorders and their families and carers. Medical speakers will be talking about different thyroid disorders, symptoms, diagnosis, medication and ongoing care and also give some practical tips and ideas about ways to manage thyroid disease. The day will also be a chance for families to meet each other.

Following on from the meeting, BTF would like to coordinate a network of families, and a working group that will focus on improving the information, support and care available. For more information or to book a place please email julia.priestley@btf-thyroid.org

‘We would like to thank everybody who sponsored us. The money raised has enabled vital research into thyroid eye disease to be funded (see page 9)’.

If you would be interested in taking part in next year’s Carrots NightWalk, which will be taking place in five cities around the UK in September 2014 (London, Birmingham, Bristol, Oxford and Glasgow), please email j.hickey@btf-thyroid.org or write in by 1 March 2014 stating which city you would be interested in. Please put ‘Carrots NightWalk’ in your subject line or on your envelope.
Christmas cards on sale

We have a selection of Christmas cards on sale at reduced prices - £2.50 including postage per pack of 10 reduced from £3.99; and £3.50 including postage per pack of 20 variety cards jumbo pack - not pictured. If you would like to buy some please email c.mcmullan@btf-thyroid.org.

British 10k London Run

Places are now available for the British 10k London Run on Sunday 14 July 2014. If you are interested in booking a place please email e.clegg@btf-thyroid.org.

Thyroid eye disease and smoking cessation leaflet

If you have been affected by Graves’ disease and/or thyroid eye disease then we would be grateful if you read a new leaflet on smoking cessation on our website (www.btf-thyroid.org - go to ‘Campaigns’ and then click on ‘Surveys’) and let us have your feedback.

May - meeting on thyroid eye disease in Newcastle

The BTF is helping to organise a public and patient event on thyroid eye disease, which will be held on Friday 16 May 2014 in Newcastle.

It is a joint venture between the European Group on Graves’ Orbitopathy (EUGOGO) and the Thyroid Eye Disease Amsterdam Declaration Implementation Group UK (TEAMeD UK) of which the BTF is a member. This will be an opportunity for patients with TED, their families and carers, and members of the public to meet European and UK experts and to find out about the latest advances, and be involved in discussions about the priorities of future research into TED. Places are limited, so if you are interested in attending please apply early by emailing info@btf-thyroid.org for more information.

BTF responds to Scottish Parliament petition

The BTF has responded to a petition to the Scottish Parliament by a group of Scottish residents with concerns about the treatment of thyroid disorders and specifically hypothyroidism.

The petition PE 01463 states: ‘Calling on the Scottish Parliament to urge the Scottish Government to take action to ensure GPs and endocrinologists are able to accurately diagnose thyroid and adrenal disorders and provide the most appropriate treatment’.

Specifically the petitioners request medical professionals ‘take account of variances in individual bio-chemistry and tailor treatment accordingly. Treatment may consist of: T4 only; T4/T3; T3 only or natural desiccated thyroid - or whatever combination to suit the individual patient. They must also provide appropriate support for adrenal insufficiency.’

Respondents include the General Medical Council, the Royal College of Physicians, and the British Thyroid Association.

The BTF response states that:

‘We know there are some patients who do not feel completely well on levothyroxine medication and we sympathise with this. However, there are issues with the solutions that the petitioners propose, and it is out of concern for safety and well-being of patients with hypothyroidism that we urge caution.

‘The latest European Thyroid Association guidelines (Wiersinga, 2012) define exceptional and experimental approaches for treating patients with a combination of T3 and T4 for persistent complaints despite thyroid hormone values within the reference range.

‘Such patients must be carefully monitored by a specialist endocrinologist and potential detrimental effects on the skeleton and heart need to be considered carefully.

‘We discourage patients from using natural desiccated thyroid products such as Armour. These products are not licensed in the UK.

‘As explained by Professor Williams at the Public Petitions Committee meeting at the Scottish Parliament on 1 October 2013, these products contain T3 and T4 in a different ratio to that normally found in humans, leading to difficulties in monitoring treatment.

Social media

The BTF has a growing online community. Our following on Twitter and Facebook broke through the 1,000 mark last year.

By the end of 2013 we had 1,033 Twitter followers and 1,007 Facebook followers.

Social media play an increasingly important role for charities and support organisations as it means we can get the word out quickly. If you would like to follow developments as they happen, join us at:

facebook

www.facebook.com/BritishThyroidFoundation

and

twitter

@britishthyroid
'We are concerned that some patients take the solution into their own hands either by consulting alternative practitioners or by ordering medicines online from websites offering T4 and T3 products as slimming aids - for example, from http://mymexicandrugstore.org [sic], as referred to in the letter from the petitioner (18 June 2013).’

The full text of the BTF statement is on the BTF website:

http://btf-thyroid.org/index.php/thyroid/statements

The full text of the petition, transcripts of committee meetings, and written submissions including the submission from the BTF, can be viewed on the Scottish Parliament website:

http://www.scottish.parliament.uk

Reference


Available to download at http://www.karger.com/Article/Pdf/339444

OUT AND ABOUT

Sight Loss and Vision PSP launched at House of Lords

Janis Hickey, BTF Director, was invited to the launch of the Sight Loss and Vision Priority Setting Partnership (PSP) report at the House of Lords on 9 October.

The report was published on the eve of World Vision Day (10 October) and marked the collaboration of individuals and organisations in prioritising questions relating to treatment, prevention and diagnosis of eye diseases.

The Lord Speaker, Baroness D’Souza, welcomed the group and congratulated all involved in the initiative. She acknowledged the enormous input in the UK of non-government organisations and the voluntary sector stating that without their input the government simply could not cope.

Lord Colwyn addressed the group and reiterated the congratulations. Michelle Acton, Fight For Sight’s Chief Executive, spoke about the report, describing the need for prioritisation so the limited resources available to researchers can be used where most needed. Given that resources for research are limited it is important that priorities are established and/or support provided.

As stated in the report, funding for eye research is limited. The findings of the Sight Loss and Vision PSP will enable existing funders to target the priorities that matter most to those affected by sight loss and eye conditions. The results will enable researchers applying for funding to demonstrate that their research targets important priorities.

The findings of the Sight Loss and Vision PSP will be communicated to funding and research agenda-setting organisations.

The Sight Loss and Vision PSP was overseen by the James Lind Alliance (JLA) which brings together patients, carers and health professionals to identify and prioritise individual questions for health research. The JLA is internationally recognised as being both authoritative and independent and is managed by the UK’s National Institute for Health Research (NIHR). The NIHR has in place a system for considering topics identified through its priority setting partnerships as part of its wider research prioritisation process.

The initiative was funded and/or in-kind support provided by the College of Optometrists, Fight For Sight, The James Lind Alliance, NIHR Biomedical Research Centre at Moorfields Eye Hospital NHS Foundation Trust, UCL Institute of Ophthalmology, RNIB, Royal College of Ophthalmologists, UK Vision Strategy and supported by many organisations including the BTF. BTF representatives Janis Hickey and Peter Foley were involved in the workshop to decide the top ten priorities in the ocular inflammatory diseases category.

Writing to thank BTF for its support, Richard Cable, FFS’s research assistant wrote: ‘The Sight Loss and Vision PSP uniquely captured the views of patients, relatives, carers and eye health professionals to identify what research into sight loss and eye conditions should be addressing. It is rare that those with direct experience of conditions are able to influence the research agenda’.

You can read the lay report by Matt Edmunds, winner of the joint Fight for Sight/British Thyroid Foundation and Thyroid Eye Disease Charitable Trust Small Grant Award 2013, on page 9.

Endocrine nurses update

Judith Taylor, BTF Trustee and Editor, represented the BTF at the Society for Endocrinology’s Endocrine Nurse Update in Stratford upon Avon in September. This is a unique opportunity to meet specialist endocrine nurses and display our patient literature, and we are grateful to the Society for Endocrinology for the opportunity to participate.

The event is a two-day residential course which is held every year and follows a three-year curriculum of topics. This year, thyroid cancer and thyroid eye disease were featured. Ex-Trustee Peter Foley gave a moving talk about his personal experience of thyroid eye disease.

Judith Taylor and Peter Foley on the BTF stand

Peter Foley talks to specialist nurses at the ENU about his own experience of thyroid eye disease
New booklet - I’ve got nothing to lose by trying it

Sense About Science, a charitable trust that aims to equip people to make sense of scientific and medical claims in public discussion, has published a new edition of its booklet I’ve got nothing to lose by trying it.

The BTF, along with the Alzheimer’s Society, Breakthrough Breast Cancer and other patient advocacy organisations, collaborated with Sense About Science to collect stories from patients who have been harmed by treatments based on unfounded claims or by ‘miracle cures’ advertised online, or hit with high costs.

Some patients said they were ‘sold false hope’ and ended up aggravating their condition, and even stopped taking their original medication.

One of these was Christine, whose story we published in BTF News in 2010 (issue 72, spring 2010).

Christine, who has a thyroid condition, is quoted in the booklet, saying that: ‘After a saliva test an “alternative thyroid doctor” gave me “adrenal glandular” tablets and told me to reduce my prescribed thyroid medication. I was in a lot of pain, bed-bound for weeks and it cost me a whole year out of my life - not to mention the huge costs of paid carers and useless and misleading saliva tests.’ Her story was highlighted in The Guardian, 16 September 2013.

Her advice to other patients is ‘not to make my terrible mistake of trusting anyone outside the medical profession.’

The examples in the booklet make it clear that the issue affects patients with many different disorders, including cancer, multiple sclerosis, motor neurone disease, autism, epilepsy, breast cancer, and Alzheimer’s.

Tracey Brown, Managing Director of Sense About Science, said: ‘If a claim about a treatment sounds too good to be true, it probably is. Families and friends can help loved-ones to ask questions and avoid exploitation.’

The BTF has a few copies of the booklet. If you would like a copy please contact BTF HQ.

New drug safety booklet

Sense about Science has also recently published a booklet to explain clinical trials and help demystify the misconceptions about drug side effects, Making Sense of Drug Safety Science: investigating the science of side effects. While it is impossible to have a drug with no side effects at all, this guide explains why they happen and what can be done about them.

The guide was developed in collaboration with the MRC Centre for Drug Safety Science at the University of Liverpool. Scientists at the centre are developing predictive tests to identify those people who will suffer extreme drug side effects. These will also allow the drugs to be given safely to other patients.

Sense about Science has done pioneering work in helping the public and patients to understand the peer review process and to weigh the scientific evidence for claims made in the press and on the internet. For more information about its publications and activities, visit http://www.senseaboutscience.org.

FUNDRAISING AND DONATIONS

If you are involved in a fundraising event in aid of BTF please get in touch so that we can send you sponsorship information, 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.

Gill William’s son Oscar and Oscar’s friend Stanley celebrated their fifth birthday party in December and decided that instead of receiving birthday presents they would donate money to the BTF as his younger brother James was born with hypothyroidism. They managed to raise £100 - thank you so much boys!

Toby, Stanley and friends celebrating their birthday

Maureen Sharp and friends from The Waggoners Folk Singers had a collection for the BTF by singing carols and raised £100.

The Waggoners

Susan Carter has given up presents and asked for donations to the BTF instead.

Jess Ling ran the Windsor Half Marathon in September to raise awareness of thyroid cancer after her step mum was diagnosed last year. She raised a fantastic £440.

Carina Nilsen completed the Great North Run (dressed as Wonder Woman!) in two hours 59
minutes and 59 seconds and raised £120! She was diagnosed with autoimmune thyroiditis and a goitre during the summer of 2012.

Jill Liddington was presented with a cheque for £500 from Hebden Bridge Rotary Club following her three-week canal walk for the BTF in the summer. This brings the grand total of her sponsorship received to an incredible £3,420. Congratulations and many thanks, Jill!

Nicola Worrall ran the Blackpool Autumn Breaker 10k run to raise money for the BTF in memory of her mum, Lynda Wilsoncroft, who sadly passed away 18 years ago. Nicola completed the run in 55 minutes and was amongst the top 20 women to complete the distance.

Katrina Rutherford and Lorraine Baylis ran the Shanghai International Half Marathon in December and raised nearly £700! Katrina is raising money for the BTF as her niece was born in September with congenital hypothyroidism.

It sounds like the run was definitely an experience! The air quality on the day was classified as ‘hazardous’ so they were both running in masks along with 10,000 others. Katrina injured her knee half way round and ended up being forced to walk the last four kilometres. She was determined to finish for her niece, however, and will be giving her the medal when she is older.

Lorraine said: ‘It wasn’t easy - I was nearly trampled by the stampede of runners, and my legs were begging me to stop about halfway, but it was a very memorable experience and knowing that we were doing it for a great cause motivated me to keep going!’

They are now both planning on tackling another run along the Great Wall of China in May to raise more funds for the BTF.

Sarah Jones ran the Bristol Half Marathon for the BTF in September and raised £135. She was diagnosed seven years ago with an under-active thyroid (hypothyroidism) at the age of 15.

Bridget O’Connor, Local Coordinator for the BTF Nottingham/Derby Support Group, had a sponsored sing with her music tutor James Mills (www.facebook.com/JamesMillsGuitarTuition) at her 60th birthday on New Year’s Day.

The night was a tremendous success and raised a fantastic £500 to be shared between the BTF and Hypopara (HPTH) UK.

Bridget said: ‘By completing our performance we hopefully demonstrated how living with any chronic long-term health condition can have a positive outcome - it is all about you controlling it rather than it controlling you.

‘For me personally it was a celebration that after going through neck/throat surgery there has been a positive outcome vocally which has enabled me to follow my passion for singing!’

A big thank you to all our fundraisers!

Future fundraisers

Syz (Simon) Goss will be taking part in ‘The Spartan Race Trifecta’ in September 2014, which 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 said ‘My 15-year-old daughter, Tiffani, was born without a thyroid gland. Thanks to fantastic medical care from eight days old, she has led a relatively normal childhood. But it is also thanks to the information and support from the BTF, which 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 with this Spartan Challenge!’

www.justgiving.com/SyzGoss

Cathryn Holman, who has been diagnosed with Hashimoto’s Disease and an under-active thyroid will be running the Brighton Half Marathon on 16 February 2014 (as we go to press). She says: ‘Without the support of the BTF I wouldn’t have been able to keep it together in the early days. So I want to give something back and help them to carry on supporting others and carry on with their research.’

www.justgiving.com/Cathryn-Holman

Somer Turnbull is taking part in the 5k Garroch Run in March. In 2012 she was diagnosed with an under-active thyroid so being able to relate to the BTF has made her want to help.

www.justgiving.com/somerturnbull
We have three runners taking part in the 2014 Virgin London Marathon:

**Simon Uddin-Wood.** Simon’s wife was diagnosed with Hashimoto’s Disease and an under-active thyroid at the age of 20 and her strength has been an inspiration to him.


**Sam Carpenter,** a thyroid cancer survivor who has been in remission for two years and wanted to do something to celebrate this and to raise money at the same time.

[www.justgiving.com Sam-Carpenter2014](http://www.justgiving.com/Sam-Carpenter2014)

and **Selim Auckburally** who has had an under-active thyroid since the age of ten and wanted to run for a charity close to him and his mum’s heart.

[www.justgiving.com selim](http://www.justgiving.com/selim)

**Heather Brookes** is walking the West Highland Way with seven friends in April.

**Bella Smith** is taking part in the BUPA Great Manchester Run in May. Her mum was diagnosed with thyroid cancer in the summer and the whole family is dedicated to raising money and awareness of this disease.

[www.justgiving.com bellasmith](http://www.justgiving.com/bellasmith)

**Donations**

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

A collection held at **John Pegg’s funeral** raised £150 for the BTF. John passed away suddenly in September. His daughter **Dannielle** suffers from Graves’ disease and her father was always a great source of support.

**Mr Docherty** donated £60 prize money from a Christmas cake competition he won. His son was born with congenital hypothyroidism 16 years ago and the whole family has found the BTF to be an invaluable source of information and support.

**Eileen Guppy** made her annual donation of £50.

**Dr Mark Vanderpump** and **Dr Tunbridge** donated royalties of £74 from their book *Thyroid Disease: The Facts.*

**Leaving a legacy**

Inside this issue of the **BTF News** you will find a copy of the BTF legacy leaflet explaining how you can leave a legacy to us in your will.

If you do decide to leave a legacy to us, you can take advantage of the reduced rate of inheritance tax of 36% (previously 40%) that came into effect from April 2012 for estates leaving a legacy to charity.

If you leave 10% or more of your estate to charity the government will reduce your inheritance tax rate by 10%.

**Shop online and raise money!**

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

**So how does it work?**

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

**How much can you raise?**

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

**Save money too!**

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

**Pilot study on ‘microRNAs’ as a new marker for thyroid cancer**

The 2013 BTF Research Award has gone to Dr Petros Perros, BSc, MBBS (Newcastle), MD (Newcastle), FRCP, Consultant Endocrinologist and Honorary Senior Lecturer at Newcastle University, with Professor Simon Pearce, MBBS, MD, FRCP, Professor of Endocrinology, Newcastle University, for their proposal for ‘An Exploratory Pilot Study of Peripheral Blood MicroRNA Markers in Patients with Papillary Thyroid Cancer’. They write:

About 2,500 people are diagnosed with thyroid cancer in the UK every year. It is one of the fastest rising cancers among women. The majority of people who are diagnosed with thyroid cancer survive for many years, but need to have regular checks as the cancer can return even 30 years after the original diagnosis. So, about 30,000 people in the UK visit thyroid cancer clinics regularly and will continue to do so for the rest of their lives.

There is a very useful blood test available called a ‘thyroglobulin test’ (Tg test), which can signal early on if the thyroid cancer is beginning to come back. A negative or ‘undetectable’ Tg test is very reassuring for both patient and doctor and such patients can be followed up less frequently. Unfortunately, in about a third of people with thyroid cancer, the Tg blood test is made useless by the presence of Tg antibodies (TgAB) in the blood stream.

About 10,000 people who have been treated for thyroid cancer in the UK have these antibodies and cannot be followed up using this test. Doctors have to rely on other ways to safeguard against the possibility of the thyroid cancer coming...
back, which are not as user-friendly as a blood test. Such patients usually have to visit the clinic more frequently for an examination of the neck, have to have frequent ultrasound examinations, and in some cases have more invasive tests such as radiiodine scans or CT scans that involve exposure to radiation. The burden on the lives of these patients imposed by the uncertainty about their cancer and the additional tests is significant and impacts on quality of life.

Since the Tg blood test was introduced in the early 1980s no other better diagnostic test has been forthcoming.

Recently a group from China made a potential breakthrough: they found another marker in the blood of patients with thyroid cancer, which was present in patients before they were treated and disappeared after successful treatment. This new test detects chemicals called “microRNAs”. They are thought to be released by circulating cancer cells. This test is not interfered with by antibodies so it can potentially be very useful for the 10,000 people in the UK mentioned above.

The work by the Chinese group is encouraging but needs to be confirmed and refined further. We believe that our research group is in an ideal position to do just that. We already have 400 blood samples collected from patients with thyroid cancer, some of whom have been cured while others still have cancer. We plan to use a laboratory in Denmark which is at the cutting edge of this technology. So, we believe that this project will be a good start and will provide some valuable information with minimum delay. It can then be expanded further, with a view to developing a diagnostic blood test that can be applied reliably to all patients with thyroid cancer, and can tell us if they are cured or if the cancer is still in their body.

Uncertainty is a terrible predicament for people with a history of cancer. We believe that our research could potentially have a huge positive impact on the lives of people with thyroid cancer.

**Charactarisation of thyroid structure and function in the PBF knockout mouse – an update**

*Dr Vicki Smith, MRC Research Fellow School of Clinical and Experimental Medicine, University of Birmingham, and winner of the 2012 BTF Research Award, has sent us this interim report about her study.*

Thyroid cancers and multinodular goitres often contain high levels of a protein called PTTG-Binding Factor (PBF). Those thyroid cancers with high PBF expression are more likely to recur and are associated with a reduced survival rate. We have previously shown that increasing the amount of PBF in mice results in significantly enlarged thyroid glands and under certain conditions can drive tumour formation. However, the way in which this occurs is still not fully understood.

We have also shown that PBF can impair the function of two proteins that are important for thyroid hormone production. One of these proteins, NIS, is responsible for taking up iodide from the blood into the thyroid and is therefore crucial both for thyroid hormone synthesis and for the treatment of thyroid cancer with radioiodine. The other protein, MCT8, is important for secreting thyroid hormone from the thyroid into the blood.

These studies highlight PBF as a protein involved in the regulation of thyroid hormone biosynthesis and secretion that, when upregulated, can disrupt thyroid cell growth, contributing to goitre and cancer. Further, the effectiveness of critical thyroid cancer treatment is reduced.

This indicates that PBF is an important regulator of the thyroid and to understand more about how it does this, the aim of this study is to characterise a mouse which does not have the PBF protein, a PBF knock-out mouse. Our main objectives are to analyse the effect of not having PBF on the size of the thyroid, on how the thyroid functions and how thyroid disease is affected.

The creation of mouse models is a complex process and, after initial successes, we have identified possible issues with the fertility of our mouse line, suggesting that PBF is also important for successful reproduction. This is a potentially very interesting observation and will be investigated further while we overcome these issues. In the meantime, we are carrying out parallel experiments using thyroid cell lines in which we can potently reduce the amount of PBF expression to provide important insights that will direct our studies in the coming months.

Overall, these studies seek to further increase our understanding of the precise role of PBF in the regulation of thyroid growth, function and disease. They will be especially important in finding ways to prevent PBF from reducing radioactive iodine uptake, and therefore improve treatment of thyroid tumours and their metastases.

This should improve therapy and outcome of thyroid cancer, particularly for the subset of patients who are currently very difficult to treat with radioactive iodine, and who have a less than 50% chance of surviving five years.

**Thermal imaging for diagnosing and monitoring thyroid eye disease**

*The winner of the Fight for Sight/British Thyroid Foundation and Thyroid Eye Disease Charitable Trust Small Grant Award 2013 was Matt Edmunds, who is a Clinical Research Fellow in Ophthalmology within the School of Immunity & Infection at the University of Birmingham. Here he explains his research study.*

Thermal imaging for diagnosing and monitoring thyroid eye disease (TED) at the earliest possible stage and in more effectively including TED is a condition involving inflammation of the tissues inside the eye socket and may be associated with distressing symptoms such as staring or bulging eyes, pain, grittiness, light sensitivity or double vision. Some develop sight-threatening complications and many have an altered physical appearance. TED occurs in up to
half of people with the form of thyroid gland over-activity called Graves’ disease. Unfortunately, there is no current way of telling which of those with Graves’ disease will go on to develop TED and it is often the case that people are diagnosed with TED too late, when the damaging effects of the eye socket inflammation are already well-established. If it were possible to diagnose TED at an earlier stage then doctors could intervene to prevent matters from deteriorating.

In people who already have TED there are other difficulties. It is often a great challenge to decide whether a person with TED has active problems which are definitely getting worse, and therefore need treatment, or has TED that has run its course and ‘burnt out’. This is a really important decision, as those with active TED require treatment with medications to control the immune system, whereas those with stable TED do not. Likewise, those with stable TED may want to consider surgery to return their facial features to as close as possible an appearance as before TED, whereas those with active TED may not necessarily benefit from surgery.

We aim to use thermal imaging to address these difficult problems. When any body tissue is inflamed it becomes swollen, red, painful and hot. Thermal imaging involves using an advanced digital camera to take photographs of how hot different areas of the body are. This is a rapid way of assessing the eyes and eye socket, essentially the same as having a photo taken (see image below).

Thermal imaging has been used before to assess people for diabetic foot problems, burns and some cancers. This technique is portable, quick, painless and easy to understand. The doctor taking the photo will be able to show each patient what the picture looks like, will be able to compare it with previous photos and will be able to decide if there have been changes between one clinic appointment and another.

The aim of our study is to perform thermal imaging in people with Graves’ disease and TED attending a specialist thyroid clinic over the course of 12 months. We believe that it will be possible to take thermal pictures on each occasion that a person with Graves’ disease or TED attends clinic, allowing us to recognise at an extremely early stage when problems inside the eye socket may be beginning in a patient with Graves’ disease, or to decide whether the eye socket of a patient with known TED is actively inflamed or not.

**BTF AWARDS**

*Each year we invite applications for two awards: the British Thyroid Foundation Research Award and the Evelyn Ashley Smith Award for nurses. We are keen to support the crucial role that researchers and nurses fulfill in providing the best treatment for people with thyroid disorders.*

**BTF Research Award 2014**

We invite applications for research that is specifically directed to the study of thyroid disorders or investigations into the basic understanding of thyroid function. The 2014 Research Award is £20,000. The deadline is 31 August 2014.

The first BTF Research Award was made in 1997. The award can be used to supplement existing projects or help get new research ideas started. Funds will be awarded for consumables, running costs and equipment.

The BTF 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.

Please see the BTF website www.btf-thyroid.org for more details and an application form.

**Evelyn Ashley Smith Award for nurses**

The Evelyn Ashley Smith Award is intended to improve care for patients with thyroid disorders. BTF is offering two awards for nurses, endocrine nurses, midwives and healthcare professionals with an interest in thyroid disorders.

The award of up to £500 is to help cover conference/training expenses, including registration fees and/or travel costs.

The award of up to £1000 is to help support a specific project lasting one year; or support an on-going project; or reward a piece of work already completed, but not yet published.

You may apply for both the £500 Nurse Award and the £1000 Nurse Award provided that each award is completed on separate application forms.

The closing date for receipt of applications is 1 July 2014.

Please see the BTF website www.btf-thyroid.org for more details and an application form.
**RESEARCH UPDATE**

Is there a benefit to iodine supplementation?

**Professor John Lazarus**, who leads the United Kingdom Iodine Status Strategy (UKISS) Group writes:

There are many groups of individuals in the UK who have iodine deficiency. Most importantly they include around two thirds of pregnant women. The iodine deficiency is mild so is there any benefit in iodine supplementation?

In a review and meta-analysis PN Taylor and colleagues concluded that iodine supplementation improves thyroid levels in some mothers and may benefit aspects of cognitive function (mental processes) in school-age children, even in marginally iodine deficient areas.

Further large prospective controlled studies are urgently needed to clarify these findings and quantify the risk/benefits of iodine supplementation in regions of the world that were previously believed to be iodine sufficient such as the UK (Taylor et al 2013).

Another recent analysis of supplementation trials by SJ Zhou and colleagues concluded that contemporary randomised controlled trials (RCTs) of iodine supplementation with outcomes addressing childhood development are indicated. However, they noted that conduct of such RCTs may not be feasible in populations where iodine supplementation in pregnancy is widely practised (Zhou et al 2013).


**BTF to collaborate in Apitope-led project to develop vaccine for Graves’ disease**

*The BTF has been invited by Apitope, a drug discovery and development company with offices in the UK and Belgium, to become involved in its Graves’ disease project.*

Apitope has developed a platform technology to identify new therapies designed to treat the underlying cause of autoimmune diseases. Its lead project ATX-MS-1467 has successfully completed a clinical trial in six patients with secondary progressive multiple sclerosis (MS) and recently announced completion with positive results of a second Phase I clinical trial of ATX-MS-1467; there was a significant decrease in the number of contrast-enhancing brain lesions (CEL) in patients with relapsing multiple sclerosis treated by intradermal injection of ATX-MS-1467.

Apitope’s antigen-specific disease-modifying peptide therapy uses epitopes designed to shut down the abnormal immune responses to the causative agent in a highly selective manner, reinstating the normal immune balance, thereby avoiding global immune suppression. As a result, the peptides taken into clinical evaluation by Apitope offer the potential to have limited side effects and a good probability of efficacy.

Peptides are compounds found in the body which consist of two or more amino acids linked in a chain. An epitope is a portion of a molecule to which an antibody, B cell or T cell binds.

Apitope is now planning to take two further projects into clinical development. One of these is a potential new treatment for Graves’ disease.

In January Apitope, announced that a consortium, led by Apitope, and which includes GSK Vaccines, Quintiles and KWS Biotest Ltd, has been awarded Framework Programme 7 (FP7) Health Innovation funding by the European Commission to develop its Graves’ disease therapeutic vaccine, including a Phase I first-in-man study in Graves’ disease patients.

The BTF’s role will be potentially to provide advice and insight into clinical plans and during the clinical trials. Dr Graham Roberts, Development Director at Apitope, says: ‘I would very much like to work with patient associations to help Apitope in the design of the clinical programme and to better understand from the patient perspective where this potential new product might provide an improved or alternative therapy to the current standard of care in the treatment of Graves’ disease.’

**Professor Neil Williams**, Chief Scientific Officer of KWS BioTest, said: ‘This is a really exciting approach to the treatment of an important human disease, which builds on the successes that Apitope has seen in its MS programme. We are looking forward to applying our expertise in the preclinical immunology and inflammation areas to help drive the project forwards into the clinic. The award of the EU grant helps to cement the close drug discovery partnership in the consortium.’

Further information about the project can be found on the Apitope website: www.apitope.com
EU grants orphan drug status to new drug to treat hypoparathyroidism

The European Commission has granted orphan drug designation to Natpara® (recombinant human parathyroid hormone (rhPTH, 1-84)) for the treatment of hypoparathyroidism.

Natpara is a bioengineered replacement for parathyroid hormone (PTH) that NPS Pharmaceuticals Inc has developed for the treatment of hypoparathyroidism, a rare endocrine disorder in which the body produces insufficient levels of parathyroid hormone, which regulates the amount of calcium in the blood. Some patients develop hypoparathyroidism after thyroid surgery and in some cases this is permanent - see Bridget O’Connor’s story in last year’s BTF News (issue 83, May 2013).

Orphan drug designation in the European Union (EU) is given to products that are designed for the diagnosis, prevention or treatment of rare diseases that are life-threatening or chronically debilitating. A disease is defined as rare in the EU if it affects no more than five in 10,000 people.

Source
BusinessWire 3 January 2014

FDA approves Nexafar to treat advanced thyroid cancer

The U.S. Food and Drug Administration (FDA) has expanded the approved uses of Nexavar (sorafenib) to treat late-stage (metastatic) differentiated thyroid cancer that does not respond to radioactive iodine treatment.

Nexavar works by inhibiting multiple proteins in cancer cells, limiting cancer cell growth and division. The drug’s new use is intended for patients with locally recurrent or metastatic, progressive differentiated thyroid cancer that no longer responds to radioactive iodine treatment.

The safety and effectiveness of Nexavar were established in a clinical study involving 417 participants with locally recurrent or metastatic, progressive differentiated thyroid cancer that does not respond to radioactive iodine treatment. Nexavar increased the length of time patients lived without the cancer progressing (progression-free survival) by 41 percent. Half of patients receiving Nexavar lived without cancer progression for at least 10.8 months compared to at least 5.8 months for participants receiving a placebo.

The FDA statement notes: ‘The most common side effects in patients treated with Nexavar were diarrhea, fatigue, infection, hair loss (alopecia), hand-foot skin reaction, rash, weight loss, decreased appetite, nausea, gastrointestinal and abdominal pains and high blood pressure (hypertension). Thyroid stimulating hormone, a potential promoter of thyroid cancer, is more likely to become elevated while on treatment with Nexavar, requiring adjustment of thyroid hormone replacement therapy.’

Source
FDA press release 22 November 2013

Letters and Comments

DIO2 gene

JH writes: I looked on your site for mention of the recent research showing that some people do not respond well to T4 alone due to the gene DIO2 (deiodinase 2 - Ed).

I am thinking of having this gene test. I am not asking for medical information, just asking if you have up to date information on the site I’ve missed.

Reference

The BTF replies: In our medical advisor’s opinion there is no clear clinical evidence that DIO2 status means certain treatment is more appropriate. To date studies of 1000s of people showed that DIO2 variants had only a small effect on thyroid hormone levels, and a large amount of further research work is needed.

Thus, the BTF cannot recommend DIO2 gene testing at this time, but will provide information should substantiated medical or scientific evidence support its proposed benefits in the future.

Should I take statins?

KF asks: I take 100mcg levothyroxine for under-active thyroid. My diet is healthy (no meat, salt, sugar etc) and I exercise regularly. My cholesterol level is 6.9. No family history of raised cholesterol. Should I take statins?

Our medical advisor replies: I understand that you are concerned by your cholesterol levels which at 6.9 is high and significantly above the recommended 5 mmol/L or less. Typically the risk to your health is further assessed by measurement of the separate amounts of low-density lipoprotein (LDL - bad cholesterol - recommended to be 3mmol/L or less) and high-density lipoprotein (HDL - good cholesterol), and possibly triglycerides.

Studies have shown that thyroid hormones act directly in liver cells to stimulate breakdown and removal of cholesterol from the liver. In hypothyroidism, cholesterol levels may be increased and the degree of change is related to the severity of thyroid hormone deficiency. Controlling thyroid function with levothyroxine may result in improvement in cholesterol levels.

We suggest you make an appointment with your doctor to discuss your thyroid function test results, symptoms, levothyroxine dose and your cholesterol levels.

If your doctor recommends and prescribes a statin to help reduce your cholesterol they will take in account the benefits and any risk of side effects.

BTF adds: Further information on high cholesterol can be obtained from the NHS Choices website.

Guides are available on our website for Thyroid Function Tests and Hypothyroidism.

Treatment with levothyroxine aims to get your TSH levels back within the reference range.

We hope that this information, together with your healthy diet and regular exercise, helps.

Adrenal insufficiency

JT asks: I have been suffering from chronic fatigue since at least 2006. In 2007 I was diagnosed with an under-active thyroid condition and take 75mcg levothyroxine daily.

In 2011 I was referred to an Endocrine Clinic to get my under-active thyroid checked and to investigate if I was suffering from Addison’s disease. Blood tests confirmed that my thyroid condition was under control on my current medication, but they advised my GP to increase my levothyroxine to 100mcg. A test for Addison’s disease revealed nothing abnormal and the endocrinologist believed that my chronic fatigue was caused by stress, which I did not agree with.

I have had numerous referrals. The explanations that I have been given so far are that I am suffering from stress or that my chronic fatigue is unexplainable.

I now suspect that I am suffering some form of adrenal insufficiency that is causing my chronic fatigue, but I cannot sustain trying to artificially pump myself up every day to generate extra adrenaline to overcome these problems.
Is it possible to have weak adrenal glands? Could I have been borderline for Addison's disease, despite the test stating that everything was normal? There is a lot of rubbish on the internet regarding adrenal fatigue mostly from people wanting you to buy their products. Where can you get safe advice about adrenal insufficiency?

I am thinking of asking my GP to send me to an endocrinologist again to have a look again for adrenal problems. Do you think this is sensible? Should I be asking for another test for Addison's disease or is there another line of investigation that can be conducted? I have read something about secondary adrenal insufficiency - Is there a test for this?

The BTF responds: Adrenal insufficiency / Addison's disease is extremely rare. Further details are available from NHS Choices.

With treatment, symptoms of Addison's disease can largely be controlled and most people with the condition live a normal, healthy life. Very few cases of polyglandular autoimmune syndromes affecting both the adrenal and thyroid glands are reported, and the symptoms are treatable with appropriate medication.

A suggested lesser condition of adrenal fatigue is a term coined by Dr James L. Wilson in 1998, author of Adrenal Fatigue: the 21st Century Stress Syndrome. It is a popular definition adopted by alternative health product providers.

We have seen no evidence that 'adrenal fatigue' actually exists. It is not described in the peer reviewed scientific literature, nor is it recognised by professional endocrinology organisations around the world.

Possible gene mutation?

SM writes: My doctor said that I might be having a gene mutation although I think my condition fits with lack of T4. However I was wondering if you could tell me what exact tests I would need to do to establish this. I am willing to even offer myself for you to do a study on my gene.

Our medical advisor replies: A possible gene mutation could mean one of several things. We presume that you have seen an endocrinologist who has performed various examinations as well as tests to differentiate between various possibilities. If not, then this would be highly recommended.

If your doctor considers you have resistance to thyroid hormone (RTH) it is a rare genetic disorder (gene mutation) in which the thyroid hormone receptor doesn't recognise thyroid hormone properly. Symptoms can vary from those of hyperthyroidism (usually palpitations) to those of hypothyroidism (tiredness, weight gain, etc) due to the varying degrees of resistance to thyroid hormones in different tissues.

As far as genetic testing is concerned, it is a requirement to confirm the exact mutation (abnormality of DNA sequence) leading to RTH. Making a diagnosis of RTH is not straightforward, and you need the help of an experienced endocrinologist for diagnosis and correct treatment.

Thyroid cysts

NB asks: Hello, I was diagnosed with an over-active thyroid in 2001, a year after my son was born. The GP at the time put me on carbimazole tablets. After one year, my thyroid level was fine so the GP said I didn't need it anymore.

I then moved house. The new GP sent me to the hospital for a scan as my glands were enlarged. I have cysts on both sides of my thyroid, and it has scanned every few years or if I have concerns.

This last month I have felt tired, dry eyes, and just haven’t felt great. I am not sure if I need to get some bloods done to check. Any feedback would be appreciated.

Our medical advisor replies: As you will be aware, a thyroid cyst is a swelling containing fluid, which is treated by removing fluid through a needle (fine needle aspiration). If this fails, then surgery may be advised. You are doing the right thing in having your thyroid scanned as required. There are guides on our website dealing with thyroid cysts.

Probably the most common thyroid disease now seen in the UK is a temporary disorder called postpartum thyroiditis, which occurs especially in women with thyroid auto-antibodies. This usually shows up in the mother up to six months after the birth. The thyroid may be a little swollen, but it is almost never painful. It usually starts with symptoms of an over-active thyroid (hyperthyroidism), which can resolve by itself but may develop into symptoms of an under-active thyroid (hypothyroidism). If it develops into hypothyroidism you may feel tired, lethargic, depressed and cold, and your skin may be dry. If this hypothyroidism persists you will need to take levothyroxine tablets.

Most women are able to stop taking these tablets after six to 12 months, but postpartum thyroiditis can return after subsequent pregnancies, so it is important to make sure that your doctor is informed and to have your thyroid tested after each birth. Further information about thyroiditis can be found on our website.

We suggest you arrange an appointment with your doctor for a thyroid function test to see whether you have hypothyroidism.

Guides are available on our website for Thyroid Function Tests and Hypothyroidism.

If you are diagnosed with hypothyroidism this is simply and safely treated with levothyroxine. It is important that your doctor starts the dose gradually taking in account thyroid function test results and symptoms. It can take five to six weeks for thyroid hormone levels to stabilise in the body and for you to feel better.

Low iodine diet

MB asks: Wonder if you can help me with food products. I am starting a low iodine diet this week, as I am going to have radioactive iodine ablation treatment for thyroid cancer, and I was wondering if I can eat porridge for breakfast? The most popular brand packet states it has traces of sodium in its nutrition but the only ingredient listed is 100% rolled oats. The Thyca.org website I consulted about foods is American and so is very confusing.

Our medical advisor replies: Reducing iodine intake before radioactive iodine treatment is important. In some hospitals people are asked not to eat any fish, seafood or dairy products for two weeks before the treatment. This makes the person relatively iodine deficient and improves the uptake of the dose.

If you wish to eat porridge, there should be no problem provided there is a long time interval between taking the porridge and taking the radioactive iodine dose as porridge is relatively high in fibre and may delay radioiodine absorption, and we suggest at least four hours.

The low iodine diet is included in our book Thyroid Cancer For Patients. By Patients which can be ordered via our website.

Hashimoto’s disease and fibromyalgia

SF asks: I was diagnosed with Hashimoto’s disease after the birth of my son 22 years ago. I had one check-up with a specialist and since then I have had nothing apart from irregular testing.

In 2012 I was diagnosed with fibromyalgia. Should I be seeing a specialist and what is the connection?

Our medical adviser replies: There is no clear evidence from clinical literature of a proven link between the thyroid disorders and fibromyalgia.

Fibromyalgia is a chronic condition of uncertain cause characterised by widespread pain, muscle tenderness and reduced pain threshold. However, most patients with fibromyalgia also report other symptoms such as tiredness after exercise, low mood, sleep disturbances, etc.

Fibromyalgia is present in about two percent of the population and is about six times more common in women than men.

There have been a number of theories regarding the exact cause of fibromyalgia.
T3 toxicosis in boy aged 10

Worried Mum asks: My 10-year-old son has very recently been diagnosed with T3 toxicosis but as he has gained 0.5kg in the last five weeks they are not going to treat it yet, just see him every two to four weeks and check his T3 levels.

As you can imagine I am now left with many questions but my biggest one is what does his future hold? Is this something that could correct itself? He has had a nuclear and ultrasound scan which showed craters which I believe are nodules and I was told if he was overweight could turn cancerous but not as likely to do so. It is possible that the relationship between thyroid disease and fibromyalgia may be coincidental since there is more case-finding due to some similarities in symptoms. For example, a patient presents to their GP with pain and/or tiredness and the GP performs a number of tests including thyroid function and it is found that there is a slight abnormality in the thyroid result. It is interesting to note that in a large population-based health fair study in Colorado, the percentage of individuals with abnormal thyroid blood tests who reported tiredness (18%) was only very slightly more than people with normal thyroid function (16%).

say that your son’s future is excellent. This is likely to be a ‘nuisance condition’ rather than something really serious.

Pregnant and hypo

Hello, I need help because I have an under-active thyroid. I take 100mcg levithyroxine daily. Currently I am eight weeks pregnant. I am worried about my child, because I suppose that my dose isn’t enough now for us. I have been waiting one month for an appointment in a hospital in Sheffield, but have not yet had a response by post and my GP and midwife can’t help.

I am scared and very disappointed. I would like just to know how many tablets I should take during pregnancy. My last TSH result was 8.5. Could you help me, please?

Our medical advisor recommends: You should take an extra 50mcg immediately (you could take two 100mcg tablets one day and one the next). Then you should have a test in four weeks and adjust as necessary. Try not to worry. It will be ok.
disorders and their subsequent treatments.

Margaret McGregor, Coordinator of the Edinburgh group, who organised the event, said: ‘The event was attended by over a hundred people and feedback has been very positive’.

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: Wednesday 26 March at 7.15pm. This will be an informal meeting.

LOCATION: Caroline’s house (Leeds 21)

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: Saturday 10 May. The group meets four times a year. Check the BTF website for details.

LOCATION: The Atrium, Royal Free Hospital, Pond Street, London, NW3 2QG. For directions and details of public transport visit www.royalfree.nhs.uk.

DONATION: Suggested minimum £3.

CONTACT: Lorraine: Tel 01843 579793 www.eventbrite.co.uk/event/9181920371

Milton Keynes

NEXT MEETING: Saturday 8 March at 10.30am. This will be a support group meeting.

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

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

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.

Newcastle

NEXT MEETING: Saturday 1 March. Check the BTF website for more details.

LOCATION: Brunswick Methodist Church, Brunswick Place, Newcastle Upon Tyne NE1 7BJ.

This is situated just off Northumberland Street, next to Fenwick and has disabled access.

CONTACT: Check the BTF website for details or email: ncsupportbtf@talktalk.co.uk

The Newcastle group is currently looking for a new coordinator. If you think you may be interested in this role please email: e.clegg@btf-thyroid.org or call 01423 709707.

Notts/Derby

NEXT MEETING: Tuesday 4 March at 7pm. The group meets every three months. Check the BTF website for more 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.

Swale (North Kent)

Welcome to Pat, our new Local Group Coordinator! Please contact her if you would like to come along to a meeting in North Kent.

CONTACT: Pat on 01795 661157 or 07799 805192. Twitter: @sheppeydragon

The BTF is very appreciative of our fantastic team: employees, volunteers, members, professionals, doctors and nurses who help the organisation to develop, as proved by our successful activities over the years.

Patrons:
Clare Balding OBE
Lord Jamie Borwick
Jenny Pitman OBE
Melissa Porter BA (Hons)
Dr W Michael G Tunbridge MA MD FRCP

Gay Search
Josef Craig MBE

Trustees:
Angela Hammond (Vice Chair)
Professor P Hindmarsh BSc MD FRCP FRCPCH
Janet Prentice BSc (Hons)
Professor Geoffrey E Rose BSc MS DSc MRCP FRCS FRCoophth
Dr M Strachan MD FRCP (Edin)
Mrs Judith Taylor BA (Hons) (Chair)
Dr M Vanderpump MB ChB MD FRCP

Ex-Officio Members of the Trustees:
Mr Richard D Bliss MA MB FRCS - British Association of Endocrine and Thyroid Specialists
Professor G R Williams BSc MB FRCS - President, British Thyroid Association

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.
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.

Belfast Ursula (U) 02892 648015
Birmingham Janet (PC,CS,RAI,PH) 0121 6287435
Cambridge Mary (O,RI,U) 01223 290263
Coventry Colin (O,RLU) 02476 711577 or 07973 861225
Edinburgh Margaret (PC) 0131 6647223
Leeds (Wharfedale) Caroline (O,U) 0113 2886393
London Lorraine (U) www.eventbrite.co.uk/event/9181920371
Milton Keynes Wilma (U) 01908 330290
Newcastle upon Tyne & North Tyneside nic support@talktalk.co.uk
Notts/Derby Bridget (GR,TS,U,PH) 01623 750330
Swale (North Kent) Patricia (U) 01795 661157 or 07799 805192

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

Carole (FC,CS,RAI) 01204 853557
Dave (PC,CS,RAI) 07939 236313
Jackie (PC,CS) 01344 621836
Gay (G,TS) 020 8735 9966
Karen (U) 01626 529212
Wilma (U) 01592 754888
Angela (U) 01943 873427

Angela (U) 01943 873427
Richard (U) 01483 576785
Olwen (O,RLU) 01536 513748
Jane (GR,RI,TED,CS,RAI) 01737 352536
Peter (TED,GR) 01200 429145
Helen (O,TS,TED) 01858 525770
Penny (Ch) 01225 421348

KEY
- Afternoons only
- 2 to 8pm Tuesdays and Wednesdays
- 2 to 8pm Saturdays and Sundays
- up to 8pm
- 10am to 12 noon weekdays
- Email only
- Full: £20 per year
- Concession: £10 per year
- Lifetime membership £200 by cheque
- By cheque
- By standing order through a UK Bank
- By sterling bank draft drawn on a UK Bank
- 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.

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Thyroid Cancer Support Group Wales Tel: 08450 092737
http://www.thyroidsupportwales.co.uk
Butterfly Thyroid Cancer Trust Tel: 02075 754549
http://www.butterfly.org.uk

BRITISH THYROID FOUNDATION DETAILS
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Next issue of BTF News: July 2014. Letters and articles should be sent to the Editor, BTF News by 1 May 2014. News from local groups should be sent in to Liz Clegg: l.clegg@btf-thyroid.org to arrive by 14 May 2014.
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