Welcome to the BTF 21 Years Anniversary issue

BTF ‘ROCKS’ AT 21st BIRTHDAY EXTRAVAGANZA

The British Thyroid Foundation was founded 21 years ago and to mark this milestone event, the BTF organised a concert in March at Harrogate’s historic Royal Hall.

A week before Easter Harrogate was transformed into a winter wonderland! But not even 48 hours of snowfall could dampen the spirits of all those who turned out for the concert at the Royal Hall to celebrate 21 years since the founding of the charity back in 1992.

The evening kicked off with an introduction by Dr Peter Hammond, Consultant Endocrinologist from Harrogate District Hospital who has worked with BTF for many years and who told the audience about the fantastic work done for thyroid patients by the charity.

Performing on the night were three groups from a family of choirs who perform collectively as ‘Rock Up & Sing!’ led by musical director, Rhiannon Gayle. The choirs - a mixed choir from Skipton, Just for Girls from Harrogate, and the newly formed Youth Choir - sang a full and varied repertoire of songs from shows like Mamma Mia, Rocky Horror Picture Show and Slumdog Millionaire as well as uplifting numbers like ‘Ain’t no Mountain High Enough’ and ‘Life in a Northern Town’.

The audience who braved the wintry weather didn’t need any encouragement to get to their feet and join in the singing and dancing. By the end of the night the atmosphere in the Royal Hall was buzzing.

Among those present to congratulate the BTF on its anniversary were the Mayor and Mayoress of Harrogate and the Mayor and Mayoress of Knaresborough.

BTF Founder and Director, Janis Hickey, who sings with one of the choirs, was delighted with the enthusiastic and large turn-out.

“We wanted to celebrate the BTF’s “coming of age” year in true style and ‘Rock Up and Sing!’ really know how to put on a show!’ she said. ‘There was a real party spirit in the Royal Hall that night and I hope that we have raised the BTF’s profile in the area greatly. We are also very grateful to so many local people and businesses who generously donated amazing raffle prizes. We have raised over £2,500 for the BTF which will make a huge contribution to the work we do.’

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‘Congratulations to BTF on its 21st anniversary. It has been a pleasure to be associated in various ways with BTF since its inception. BTF has been of enormous help to many people with thyroid disorders and their relatives. BTF has also forged a strong link with the British Thyroid Association of professionals involved in the care of patients with thyroid diseases and has been generous in supporting thyroid research in practical ways. It is a privilege to be a Patron of the BTF and to encourage support for all its activities. May it go from strength to strength.’

(Michael Tunbridge, MA, MD, FRCP, thyroid specialist)
NEWS FROM BTF HQ

Important message to members who pay by standing order

Firstly, we want to thank all members for your support over the past 21 years! We are very grateful for your continued support to allow us to carry out our work.

Like everyone in Britain, small charities have to watch every penny to enable them to function as intended. Our membership database shows us that not all standing order members are paying the current subscription (i.e., £17 for those in employment and £8.50 for those in retirement or unwaged).

We have therefore had to take a decision that we can no longer supply the newsletter to people who do not pay the current subscription rate, because of the cost of producing and posting it.

If your subscription is lagging behind for whatever reason, please ask your bank to increase your standing order accordingly.

We know that many members generously pay more than the subscription rate and we are very grateful for this. We don’t write to acknowledge this in individual cases as we don’t want to spend their ‘extra’ on postage when it is meant for core use.

Carrots NightWalks

If you are looking for a unique fitness challenge, then join us on one of these fun night time walks around four UK cities organised by Fight for Sight.

The 15- and six-mile Carrots NightWalks are being organised in London, Glasgow, Cardiff and Birmingham and bring together supporters of many charities and organisations who have an interest in raising funds for research into eye disease.

This year’s walks take place on 20 September 2013. If you are interested in taking part, and think you can raise between £120 and £250 (or more!) then please email: j.l.hickey@btf-thyroid.org with the subject header: ‘Carrots NightWalk’. If we can get together 30 people and raise £7,500, this will be matched by the eye organisation Fight for Sight who are supporting this event and will enable a thyroid eye disease research project to take place. BTF will be working with Thyroid Eye Disease Charitable Trust (TEDct) on this project.

If you can’t make the walk but would like to donate please go to our JustGiving page www.justgiving.com/btf-roots-in-boots

Farewell to…

Carole Ingham who is sadly stepping down as Local Coordinator for the BTF Bolton group after running a very successful group for 13 years where she was supported by a team of helpers and her husband Ian. Running a local group wasn’t the only thing she was involved in though; she was a BTF Trustee from 2001 to 2012 and was Chair from 2009 to 2012.

Carole was one of the key people involved with the first edition of the thyroid cancer booklet and the lead in the BTF Thyroid Cancer Group until 2011. Carole was very active in promoting the BTF and representing the charity on many occasions and supported many people through telephone calls and local group meetings.

Carole manning a stand with BTF thyroid cancer information

Judith Dryhurst who is stepping down as Local Coordinator for the BTF Newcastle group due to health reasons. Judith has been running a successful group since March 2009 and her good work will be continued by new coordinator Julia Charlton.

We know you will all join us in wishing Carole, Ian and Judith well.

Sue Sherwood, Lucy Motherwell and Denise Hannagan who have stepped down from their roles as telephone contacts.

Dianne Wright who has stepped down as a Trustee. Dianne is a specialist endocrine nurse and joined the Board of Trustees in March 2007. We are very grateful to Dianne for her huge input, and especially for promoting the BTF Evelyn Ashley Smith Nurse Awards.

We would like to thank all four for their support and dedication.

Welcome to…

Our new Trustee Jennifer Linley, who has also taken on the role of BTF Treasurer. Jennifer was originally a BTF volunteer, joining us in 2009, and was subsequently employed on a part-time basis, before retiring in 2012 and once again offering her services on a voluntary basis. Jennifer has played a key role in organising the accounting system, and reconciles the accounts each month.

One of our Trustees, David Fortune has been awarded the Vodafone ‘World of Difference’ sponsorship to work on the implementation of a quality management system in the BTF office from March to June.

These boots are made for walking...

After the successes of the last couple of years’ BTF Big Summer Walks we are again asking our supporters to get their boots on for us.

The walk is open to everyone and it is really easy to take part. All you need to do is gather your family or a few friends together and organise a walk of any length (or bike ride/run/trek) between 21 June and 21 September 2013. Then tell everyone you know and get them to sponsor you. You can set up a JustGiving page or call the BTF office if you would like sponsorship forms.

You can register on the BTF website (www.btf-thyroid.org) or call the office (01423 709707) to request a registration form.

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Parents’ and carers’ guide

The BTF has produced a comprehensive guide for parents and carers of children with thyroid problems. Called Thyroid conditions in babies, children and young people: A guide for parents and carers, it can be found on the BTF website under ‘Your Thyroid’.

The guide was prepared by a team of volunteers and parents including Pam Cowburn, who led the group and over many months applied her expertise in writing to develop the working group’s initial concept. Also involved were our medical advisors Professor Peter Hindmarsh and Dr Tim Cheetham, Paediatric Endocrinologists.

The guide is a comprehensive resource for parents and carers faced with a diagnosis that their child has a thyroid disorder. It includes the stories of children with thyroid disorders including Tom, who was diagnosed with thyroid cancer at the age of three, and Danielle, who was born with congenital hypothyroidism and now has a healthy child of her own.

The guide has sections on the thyroid gland, hypothyroidism, hyperthyroidism, thyroid eye disease, and thyroid cancer. It also contains useful information about levothyroxine, antithyroid drugs, a glossary of terms, and a list of useful contacts.

Launching the guide, BTF Director Janis Hickey said ‘Thyroid disorders are not common in children, which means that it can be hard for parents and carers to find responsible information and support. We saw there was a gap that badly needed to be filled and this guide is the result.

‘The guide was written as a result of consulting with parents and carers about the sort of information they would like to have had when their child was diagnosed.

‘I would like to thank all the volunteers who contributed in various ways and especially Pam Cowburn who took on the lion’s share of writing and editing the guide.’

Hair loss

The BTF is currently gathering information for an article on hair loss and we would like to incorporate our members’ experiences of this, as we know it is a very common and often distressing problem. Please email Janis Hickey at j.hickey@btf-thyroid.org if you would like to share your experiences or have any hints and tips that may be helpful.

Legacies

The BTF is producing documentation for our legacies programme that we hope to have ready later in the year. Legacies are a vital source of income for our work and enable us to continue funding research projects into thyroid disorders that are so urgently needed.

We received £86,000 last year from legacies. Some of this is already earmarked for hypothyroidism research. Both the BTF Research Award and the Evelyn Ashley Smith Nurse Award that we offer annually are funded by a legacy of £190,000 left to us by long-standing member Evelyn Ashley Smith.

If you would like any further information about leaving a gift in your will please call our office on 01423 709707.

BTF supports AllTrials campaign

The BTF has joined over 250 organisations in support of the AllTrials campaign - an initiative of Sense About Science, the British Medical Journal, Cochrane Collaboration, Bad Science, the Centre for Evidence Based Medicine and the James Lind Initiative. The campaigners are calling on governments, regulators and research bodies to implement measures to ensure that all clinical trials are registered and their full methods and the results reported. For more information see www.alltrials.net.

MHRA strategic plan launched

The Medicines and Healthcare Products Regulatory Agency (MHRA) has now published its five-year corporate plan 2013-2018.

The BTF was one of the organisations that submitted comments on the draft plan when it was circulated last year.

In its submission, the BTF stated it welcomed the aim of the MHRA to provide patients and public with ‘personal choice and autonomy in health care while offering robust protection against risk’ and encouraged the MHRA to work more closely with patient charities to achieve this.

OUT AND ABOUT

Patients help establish priorities for eye research

Representatives of the BTF were among those taking part in the Sight Loss and Vision Priority Setting Partnership (PSP) Final Prioritisation Workshop for Ocular Inflammatory Diseases which took place in London on 16 April.

Supporting the need for thyroid eye disease (TED) research were Peter Foley and Janis Hickey, representing the BTF, and Dan Ezra (Consultant Ophthalmologist, Moorfields Eye Hospital). Other eye diseases in the ocular inflammatory diseases category included birdshot retinopathy, uveitis, Behçet’s syndrome, and scleritis.

This was one of a series of priority-setting workshops organised by Fight for Sight (FFS) in conjunction with the James Lind Alliance to which patient representatives and healthcare professionals were invited.

The workshops were held following a major survey last year, which was widely advertised by the BTF and other eye disease groups to ask patients, their families and carers, and healthcare professionals to help identify which areas of eye disease should be made a priority for future funding (see BTF News 81). The results will inform FFS’s research agenda as well as being promoted to other funders and researchers.

Several major funders of eye research collaborated in this venture, including Fight for Sight (FFS), The College of Optometrists, The Royal College of Ophthalmologists and the National Institute for Health Research (NIHR).

The aim of the survey was to find out what questions on prevention, diagnosis and treatment of sight loss and eye conditions the participants would like to see answered.

The survey attracted 2,200 participants and 4,461 questions. A data assessment group divided the questions into 12 different categories, one of which was ocular inflammatory diseases (OID), and by looking at existing evidence bases and information from the Cochrane Eye and Vision Group was able to establish whether the questions were unanswered or whether uncertainties remained. The number of questions about ocular inflammatory eye disease reduced from 450 to 66 unanswered questions. A long list of unanswered questions was drawn up for each eye disease category for the interim prioritisation exercise and circulated to relevant patients, carers and healthcare professionals who were invited to choose their top ten.

The results of the voting exercise were collated to produce a final shortlist of 30

Continued on page 4
questions for discussion. There was a good response from patients with TED, and questions about TED were well represented.

The workshop participants were asked to reflect on and discuss their views of ocular inflammatory diseases and the short list of uncertainties, and together agree the 10 most important uncertainties. The result was:

1. What are the most effective treatments for ocular and orbital inflammatory disease?
2. What causes thyroid eye disease?
3. Can the severity of ocular and orbital inflammatory disease in an individual be predicted?
4. Is it possible to prevent further occurrences of retinal damage caused by toxoplasmosis?
5. What causes birdshot retinopathy?
6. Why does disease burn out in patients with ocular and orbital inflammatory disease?
7. Can early detection methods be developed for ocular and orbital inflammatory disease?
8. What medications best prevent the development of eye disease in Behçets?
9. What causes scleritis?
10. Can diet or lifestyle changes prevent uveitis from developing?

The top questions from this workshop, together with those from the other 11 eye disease workshops, will be forwarded to the NIHR panel for consideration for research funding.

The original wider questions will become part of the UK Database of Uncertainties about the Effects of Treatments (UK DUETs), part of NHS Evidence. The James Lind Alliance Priority Setting Partnership will raise awareness of these unanswered questions, which will also be published on the FFS website and in an eye journal.

Further information on Priority Setting Partnerships (PSPs) and the work of the James Lind Alliance in promoting the importance of patient, carer and clinician involvement in research priority setting, can be found at www.jla.nihr.ac.uk.

Moberly and Stephen Robinson.

The QOF is a system for the performance management and payment of GPs in the National Health Service. The QOFs reward GPs for implementing good practice in their surgeries. The scheme was introduced in 2004 as part of the new general medical services contract.

There are 18 clinical domains for which GPs can accumulate QOF points. Hypothyroidism is one of these.

The article is published in Medeconomics - the Business of General Practice which is a companion publication to GP Magazine. (The article is behind a paywall.)

Reference
Tom Moberly and Stephen Robinson. QOF domain: hypothyroidism. Medeconomics. 4 September 2012.

Low iodine levels

The Times has published a letter from members of the UKISS group (see below) calling for the Department of Health to consider implementing corrective action by the iodisation of salt used in the household and in food manufacturing processes.

The letter, published on 6 May, was in response to an article in the 1 May issue of The Times which expressed concern about the iodine status of the UK.

UKISS lead calls on Welsh government to address causes of iodine deficiency

Shocking levels of iodine deficiency found in Welsh schoolchildren ‘risk causing mental impairment in future generations’, according to Professor John Lazarus, former BTF Trustee and Project Leader of UKISS – the United Kingdom Iodine Status Strategy group.

Professor Lazarus has called on the Welsh Government to take a leading role in addressing the causes of the deficiency, which was confirmed in a study he and colleagues undertook involving around 900 15-year-old schoolgirls in Cardiff and eight other British cities. His remarks are reported in an article that appeared in the Western Mail and on Wales Online (see reference).

A Welsh Government spokeswoman is reported as saying that ‘We are committed to improving the health and well being of the people of Wales and to reducing health inequalities.

‘As part of our Big Health Debate surrounding the proposed Public Health (Wales) Bill, we welcome all contributions on ways to improve health in Wales, including those of Professor John Lazarus.’

Reference

BTF PROJECT UPDATES

Thyroid disease in children

Julia Priestley writes: In the last newsletter we told you about the animation we have created with the help of grants to provide information and support for children with thyroid disorders. We have widely promoted the availability of the animation and have received very favourable feedback about it.

We have recently been contacted by some European patient support groups who have requested a license to use the animation on their website.

We have also produced a new children’s poster that is to be displayed in clinics advising of the support that the BTF offers and a new parent/carer guide is now on the BTF website (see page 3).

During the next few months we would also like to organise and host a children’s conference at which medical advisers can provide support for children and their families.

Iodine status in the UK

Janis Hickey writes: The project is gaining momentum and people are starting to take notice. As reported in BTF News 82, January 2013, the UKISS (United Kingdom Iodine...
**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 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.

**Emmett Hynes** completed the Men’s Health Survival challenge in November and raised £120. The event was a 10k obstacle course based around East Manchester and Manchester City’s football ground. Emmett completed the course in one hour and twenty minutes and told us he was completely shattered swimming across the three canals but that this was nowhere near as bad as the climbing frames! He said the mud slide was an absolute thrill and just eclipsed the joy of running around Manchester City’s hallowed turf!

A group of ladies from Formica (Newcastle) held a coffee morning and baked cakes instead of sending Christmas cards and raised £42.50. Thanks ladies!

**Haylee Ann** raised £149 by taking up the Marcothon challenge. She had to run every day for at least 25 minutes (or 5km, whichever came first) for every day in December including Christmas day! Her motivation was her brother who has recently recovered from thyroid cancer. Thanks for your dedication Haylee!

**Courtney Turner** has raised a fantastic £780 so far in memory of her father **Garry** who suffered from an under-active thyroid for the majority of his life and often struggled with the physical and mental implications of the condition. His thyroid caused him to retire early from work because he was often too ill to carry out his day to day activities and it also had an impact on his mental health which was difficult for his family to deal with. He became increasingly frustrated that many medical professionals didn’t understand the thyroid as much as they could with further investigation. This is one of the reasons **Courtney** selected the British Thyroid Foundation as it was an important cause for both him and Courtney’s family, many of whom have also been affected by the disease.

**Courtney’s cousin, Dean Turner** is also completing a challenge in memory of Garry. He will be taking part in a sky dive in August even though he is frightened of heights!

www.justgiving.com/Dean-Turner1

**Michael Dyson** took part in a triple whammy (zip wire, abseil and power fan) on 9 March and raised nearly £300. He said ‘The power fan was a bit scary as it is designed to simulate a parachute jump, so you freefall for three quarters of the way down and then friction kicks in and slows you down to the ground. All in all though it was good fun and I enjoyed it’

Dean Sharman completed the Paris Half Marathon on 3 March and raised nearly £400! Dean had been due to run with his brother and step daughter Bill and Jess but due to unforeseen circumstances they had to withdraw from the race. Both have now signed up for the Windsor Half Marathon in September and will continue with their fundraising.

www.justgiving/Bill-Sharman and www.justgiving.com/Jessica-Alice-Ling

Dean said ‘I think that I was the sole representative for the BTF in Paris and the BTF t-shirt raised a lot of questions from other runners. As I live in France just south of Limoges my wife and I travelled to Paris by train leaving at 6am on the Saturday morning arriving in Paris just after 9am. After completing the registration for the event we then spent the rest of Saturday visiting as many tourist sights as possible (not a good idea before a half marathon!).

‘On the Sunday morning feeling a little stiff after many miles walking the streets of Paris it was time for the race. The weather was a fantastic cool bright sunny day and the organisation was very good as there were over 35,000 runners. The run was hard work but fun and there was plenty of support along the route. I finished in two hours and 40 minutes, a bit slower than expected but I put that down to the sight-seeing the day before (and a large meal the night before!).

‘I would like to add that if anyone else is thinking of doing a challenging event like a half or full marathon that it is a lot easier to carry out his day to day activities and it also had an impact on his mental health which was difficult for his family to deal with. He became increasingly frustrated that many medical professionals didn’t understand the thyroid as much as they could with further investigation. This is one of the reasons **Courtney** selected the British Thyroid Foundation as it was an important cause for both him and Courtney’s family, many of whom have also been affected by the disease.

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Continued from page 5

get over the aches and pains than it is for somebody to battle and beat cancer - just keep this in mind as motivation on those cold wet training runs.'

Steve Robb and Andy after completing the Aberdeen Ultra Marathon

Duncan Scott completed the Aberdeen Ultra Marathon (33 miles!) in five hours and 58 minutes on 16 March and raised over £650 for the BTF! His daughter Jocelyn has congenital hypothyroidism and is thriving on a daily dose of levothyroxine and the lovely Scottish outdoors! He said the run was ‘tough but enjoyable, especially when getting a beer at the end. Thanks so much for all the very generous support, which has far exceeded my expectations. I would also like to thank my wife Anna for all her help’.

Duncan Scott and Andy after completing the Aberdeen Ultra Marathon

Rob said ‘My inspiration as always is Eilidh, my daughter, who was three in May. Eilidh was born without a thyroid but thanks to early and routine testing this was discovered and she leads a normal life. It is so crucial that we continue to fund research into thyroid conditions in children and help as many families as possible.

‘None of what has been achieved in 2011 and 2012 would have been possible without the support you all offered, and that of those close to me, particularly Natalie (my wife) and Eilidh who were there every step of the way. My thanks I offer to them and you all.’

www.justgiving.com/Stevenrob79

Sue and Peter Robertson held a classical concert on Saturday April 20 at St Mary and All Saints Church, Filongley near Coventry. They were joined by a string quartet ‘Cantabile’ and some of their talented singing friends. They raised nearly £1000 for the BTF!

Matthew Jenkins ran the Balfron 10k for the BTF on 28 April and raised over £400. His partner Lesley Antrobus who ran last year for the BTF unfortunately had to pull out at the last minute for emergency spine surgery. Lesley’s daughter Becky has congenital hypothyroidism and has found the BTF a source of continuous support.

She said: ‘Thyroid disorders are relatively uncommon in children. Once they have left the hospital with a diagnosis many parents feel at a loss when questions arise about symptoms, treatment, care and future health. With limited research and information to hand this can be very overwhelming and having experienced this first hand it’s a scary thing to go through with your newborn.

‘No amount of personal research could answer my questions and give me the information I needed until I was put in touch with this foundation and their specialists. Their support for Becky has been incredible.’

Ruth Bisbrown Chippendale is raising money for the British Thyroid Foundation in memory of one of her closest friends who died rapidly of wrongly diagnosed highly malignant thyroid carcinoma. Ruth has joined a gym and is going for three days a week doing a variety of classes as well as a programme to get fit for a long walk this summer.

A big thank you to all our fundraisers!

Future fundraisers

Nikki Brady, one of BTF’s trustees is running in three Jane Tomlinson’s 10k Run for All events in Hull, Leeds and York throughout the summer.

www.justgiving.com/Nikki30k

Stephanie Stacey is running the Edinburgh Marathon on 26 May 2013 (as we go to print). Stephanie and her husband Luke have made a pact to raise £1,000 for the BTF every year until their daughter Evelyn, who was born without a thyroid is 18. Luke has already raised a fantastic £490 from a charity boxing match earlier in the year. To help Stephanie in her quest to exceed that amount, go to www.justgiving.com/Stephanie-Stacey.

Emma Husband and Kieren Balkwill will be running the BUPA Great Manchester Run on 26 May 2013 (as we go to print). Kieren said ‘I’m running to raise money for the BTF as I am one in twenty.’ Kieren was diagnosed with hyperthyroidism recently and wants to raise awareness of the condition.

www.justgiving.com/kierentc

Lauren Bishop Vranch is completing a 100k cycle race at night, the ‘London Nighttrier’, on 8 and 9 June. She was diagnosed with a thyroid condition as a child and says ‘there was hardly any information available about it. We were given lots of misinformation too - that it isn’t hereditary, that it can be controlled by diet. As a result, I wasn’t diagnosed or treated properly for a lot longer than should have been the case. She added ‘Having never cycled more than 6 miles at once, it’s a pretty big challenge and I’m quite nervous. I’m training every other day to improve my stamina and cycling skills and I’m sure the sponsorship will make it all worthwhile! I’m at 75% of my target now, so I really hope to break that before the big night!’

www.justgiving.com/LaurenBishopVranch
Liz Wall will be taking part in three runs throughout the summer for the BTF: Harrogate 10k on 21 July, York 10k on 4 August and the BUPA Great North Run on 15 September. Liz had a long and painful journey before being diagnosed with hyperthyroidism and says her reason for wanting to raise money for the BTF is to help promote a greater awareness of thyroid disorders amongst the general public and the medical profession and to raise funds for research.

www.justgiving.com/lizzie-wall

Carina Nilsen is also taking part in the BUPA Great North Run in September after being diagnosed with autoimmune thyroiditis and goitre during the summer of 2012.

www.justgiving.com/carina-nilsen

Sofia Albohaithi is running in two half marathons and a 10k for the BTF! Her first run was the exotically titled Madrid Rock n Roll 10k on 28 April 2013. Her second is the Edinburgh Half Marathon on 26 May and the third is the Lakeland Trail Half Marathon in Coniston on 7 July 2013. She says ‘I have been wanting to raise money for the BTF for a while. I have had practically every problem that the thyroid can cause over the last eight years so it really means a lot to me!’

www.justgiving.com/sofiaalbohaithi2

Andy Kirk and his friend Andy Garrison (aka the two Andys: Big and Little!) are planning a heroic cycle ride on 20 July from Kettering (Andy Kirk’s home town) to Monaco, roughly 1,000 miles! Andy said ‘We both graduate from university this summer and before entering the big wide world of work and focusing on our careers we would really like to do something for charity. As we both enjoy cycling around Yorkshire we came up with this plan. We propose to complete the ride within 14 days. People who are close to me suffer from thyroid conditions so we would really like to raise money for the charity’.

www.justgiving.com/Big-and-Little-Cycle

Jill Liddington completed a 10 mile sponsored walk last year for the BTF. This year she is planning an ambitious three week walk from the north of England to the south during July, which she invites you to support. She will follow canal towpaths from West Yorkshire down to London. For Jill’s new justgiving page and for dates and the route, please go to www.btf-thyroid.org - Get Involved – Jill Liddington’s Canal Walk. http://bit.ly/11BZzuG

British 10k

We have six runners running for the BTF in the British 10k Race in London on 14 July 2013. Two of them are BTF volunteers - Lorraine Williams who runs the BTF London Support Group and John Challis www.justgiving.com/John-Challis who runs the Brighton Support Group. The other runners are Lisa Jones www.justgiving.com/LisaBellinghamJones, Lucie Gaunt, Alison Duggall and Katja Gomer.

Good luck to all our future fundraisers!

Donations

Doreen Peacock left £15,000 in her will.
Eileen Guppy donated £50 (many thanks for your contribution each year).
Julie Heaton-Harbuton donated £10, money she saved from not sending out Christmas cards this year.
Vivienne (a BTF volunteer) and her husband Phil Rivis donated £52 in lieu of their joint ‘When I’m 64’ party.

Helping to raise funds for the BTF

Monkey is a car insurance comparison site that makes donations to charities when policies are taken out. They have donated £300 to the BTF and if you sign up for a policy with them using the following link they will make a £10 donation to the BTF: www.monkey.co.uk/british-thyroid

BTF is now registered with eBay for charity!

You can support the BTF whenever you sell an item on eBay. When you’re listing the item, just choose the charity you want to support and the percentage you want to give. You can support charities when shopping by buying items marked with the eBay for Charity ribbon, or by making a donation to a featured charity when you pay for an item through eBay. See: http://pages.ebay.co.uk/ebayforcharity/charities.html for more information.

BTF Research News

BTF Research Award 2013

The 2013 BTF Research Award has been increased to £20,000. 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 deadline is 31 August 2013.

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.

The winner of the 2012 BTF Research Award was Dr Vicki Smith from the School of Clinical and Experimental Medicine, University of Birmingham for her proposed study on ‘Characterisation of thyroid structure and function in the PBF knockout mouse.’ (See BTF News 82, January 2013, for an outline of her proposed study.)

For more details and an application form please see the BTF website.

BTF Nursing Awards 2013

The deadline for the Evelyn Ashley Smith Nurse Awards is 1 July 2013. There are now two nurse awards: one of £1,000 for a project and one of £500 towards training or attending conferences. More details and an application form are on the website.

Evelyn Ashley Smith Nurse Awards 2013

Applications are now open for the Evelyn Ashley Smith Nurse Awards 2013.

The awards are open to nurses who are currently working with patients affected by thyroid disorders or are planning to do so.

There are four awards available:

1. The Clinical Nurse Award comprises £1,000 plus travel expenses to attend conferences.
2. The Nurse Award comprises £500 plus travel expenses to attend conferences.
3. The BTF Nurse Awards comprises £1,000.
4. The Nurse Awards comprises £500.

Applications should be submitted via the BTF Nursing Awards online form. The closing date is 1 July 2013.

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(photos by Bill Waters)

‘BTF has been hugely supportive to me and my loved ones during my experience of thyroid cancer. Your support will help the charity grow. Thank you.’ (Clare Balding, TV and radio presenter and sports commentator)
RESEARCH UPDATE

Patients need to be better informed about side effects of antithyroid drugs, says study

It is important that doctors provide high quality of information received by patients regarding the side-effects of the drugs they are taking. This is especially so with the antithyroid drugs used to control hyperthyroidism as they have serious side-effects in a small number of cases.

In 2012, 100 patients who were taking antithyroid drugs completed an online survey which was designed by Jonah Robinson, a sixth former at the Royal Grammar School, Newcastle. The aim of this survey was to ascertain the quality and format of information received by patients about what they should do if they experienced symptoms suggestive of agranulocytosis, an uncommon but serious side-effect of antithyroid drugs. The survey also looked at improvements to the quality of information given, and patients’ ability to recall this information. Here is a summary of the results.

Hyperthyroidism affects approximately one percent of the adult population. Antithyroid drugs (carbimazole or propylthiouracil) are commonly used to control hyperthyroidism. Some patients with hyperthyroidism elect to have lifelong treatment with antithyroid drugs, rather than one of the alternatives, and there is evidence that long-term treatment with antithyroid drugs is usually well tolerated.

A small percentage of patients on antithyroid drugs do however experience side effects. One of the most serious of these is agranulocytosis, where the patient’s concentration of granulocytes (a major class of white blood cells) drops to less than five percent of the normal value. Although it has a relatively low frequency, it is unpredictable; the risk increases with greater doses of antithyroid drugs.

Agranulocytosis usually presents with a sore throat, fever and mouth ulcers. It is standard medical practice to advise patients about this side-effect and to instruct them to seek urgent medical advice and a blood test, should they develop symptoms suggestive of agranulocytosis. This advice is usually given verbally and supported with written information in the form of a leaflet. Packet inserts of antithyroid drugs also contain written information about seeking medical advice if warning symptoms occur.

Patient education regarding the serious side-effects of antithyroid drugs is agreed as being a fundamental and important part of management of patients receiving this treatment. Previous audits in the UK on the level of information recalled by patients on antithyroid drugs have indicated that approximately 50% recalled appropriate action. It was unclear though from these audits whether patient knowledge was time-dependent. Also no feedback was sought from patients on how to improve their knowledge.

The analysis of the 2012 survey results showed that 70% of patients were aware that there are serious side-effects of the medication they were taking. When asked how they received side-effect information (multiple choices were possible), the insert in the drug packet was most common with 56% of responses.

When asked about their confidence in their knowledge of the side-effects, however, only 43% were ‘confident’ or ‘very confident’, with 23% ‘not confident at all’.

Patients were asked what they would do if they got a sore throat (a symptom of agranulocytosis) whilst taking their medication. Despite the majority being aware of the serious side-effects of antithyroid drugs, less than half said they would make an appointment with their GP on the same day if a symptom appeared. 21% would wait until the next day and then decide what to do. Only four percent said they would conduct an internet search.

Regarding the quality of information patients received about the side-effects of their medication, only nine percent said it was ‘excellent’. 33% thought it was ‘ok’, and 22% ‘not good at all’.

The majority of patients said they would prefer to receive extra information in person with a health professional. Eighty-nine out of the 100 participants thought more information was needed about the drug side-effects. When asked how they would prefer to receive it (more than one option available), 73% would want to speak in person with a health professional, 27% by letter, 18% said by email, and three and two percent said by text message or telephone respectively.

In conclusion, although there are many sources of patient information about the side-effects of antithyroid drugs, and all patients received information about the side-effects in some form (from a GP, drug packet information sheet etc.), it is evident that the majority require more information. Every patient should have the opportunity to speak to a health professional in person and discuss the side-effects of their antithyroid drugs.

The study recommends that improvements to practice should be made to ensure that all patients are able to be confident in the knowledge of the side-effects and the action taken upon discovering symptoms implicit of the side-effects. All patients taking antithyroid drugs should be offered the chance to discuss side-effects and information regarding them with a health professional on a regular basis; 73% of patients wished to receive further information in person with a health professional. This survey suggests that a ‘one off’ discussion of side-effects of antithyroid drugs may be insufficient to allow patients to respond appropriately to symptoms of possible agranulocytosis.

‘I would like to congratulate BTF on its 21st birthday. It was 1998 when I was diagnosed with thyroid cancer and I was in a dark and unknown place. The information I received from BTF was a great comfort: it feels as though someone is holding your hand. To read of other people’s experiences, and additional information regarding treatment, is reassuring as many others have been in the same situation and are now fully recovered. Thank you BTF from your many supporters.’ (Jenny Pitman, OBE, racehorse trainer)
Tell us first about your own thyroid journey

I was diagnosed with Graves' disease (over-active thyroid) in 1984, aged 29. Funnily enough, thyroid disorders are one of the few bits that I remember from my biology class, particularly that tablets used for treating hypothyroidism were sold as slimming tablets for many years.

I discovered later from my mother that her father had also had Graves’ disease but died shortly after having a thyroidectomy in 1938 when he was just 36. My mother was only six, so I never knew about this family connection until I was diagnosed myself. Two (female) cousins on the same side of the family also have an over-active thyroid.

I was treated first with carbimazole and later by ‘block and replace’. I never had radioactive iodine or surgery, but remained on tablets for the duration of the over-activity until it burnt out in about 1997.

I had noticed something wrong with my eyes even before I was diagnosed with Graves’. I was blinking a lot and looked a bit startled all the time. I thought I had an infection, and got quite frightened and panicky.

The first GP I saw told me I had conjunctivitis… and gave me the same diagnosis when I returned a few weeks later (having lost a lot of weight). I remember he said ‘Conjunctivitis doesn’t clear up in a couple of weeks my dear’. I had all the classic signs of thyroid eye disease (TED) and Graves’ disease but he missed it!

One day I mentioned to a friend who used to be a nurse (and who later became a BTF Trustee) that when I put my hands over my eyes it felt as though my eyes were ‘sticking out’. It was she who first mentioned the word ‘thyroid’ and suggested I see another doctor. The next GP I saw was very good. I had the blood test and started treatment and he looked after me very well, especially during my two pregnancies. He referred me to an endocrinologist, although due to administrative errors I never actually saw one until 1987.

I had my first child in October 1985. September 1985 was quite an anxious time as my obstetrician decided the baby was ‘too small’ and that I should spend ten days in hospital undergoing tests. Well, everything turned out okay. Eleanor was born, she had antibody tests and we were visited by special care midwives for the first month. My son Matthew was born two years later. Of course I still keep a keen eye on both my children.

My thyroid health is now fine, but the eye disease was distressing and depressing for a long time. Finally I met a surgeon who said he could help me.

I had orbital decompressive surgery on my eyes in 1998 and it changed my life, restoring my self-confidence and allowing me to move on. I am now under-active and take levothyroxine although I still consider myself an over-active person!

How did the BTF get started?

As you’ve perhaps gathered it was the TED rather than the hyperthyroidism that bothered me. I was so fed-up that I had this disease, which, I eventually realised, was not going to go away. I’d never met anybody with TED, and felt quite lonely. I tried to find information, but there were only medical books (frightening!).

I realised there must be other people in a similar position to me. So I set out to find a support group. I couldn’t find one in the UK, but discovered there was a recently-formed Thyroid Foundation of Canada. They confirmed my suspicions that there wasn’t a support group in the UK and asked why didn’t I set one up myself?

They mentioned the Thyroid Foundation of America had just been established, so I contacted Professor Larry Wood, the founder, and he gave me the contact details of Sir Richard Bayliss, a well-known thyroidologist, and former physician to the Queen, to whom I wrote.

Sir Richard was immediately strongly supportive of the idea to establish a thyroid foundation in the UK. He very much believed that patients should be well-informed, and he cared very much for their well-being, often giving his home telephone number to his patients so they could contact him if concerned. We became very good friends.

I spoke to my husband about ‘the plan’ because I knew I would need his support. In 1989-90, when the initial plans were being laid, my children were just four and two years old, and I was also working.

Fortunately, I have always felt supported by my friends and family, though, in retrospect, I don’t think I actually realised at the time just how much the BTF would grow, how much need there was out there for support and information, and how much work it would involve.

Encouraged by Sir Richard’s response I spoke to my endocrinologist, Dr Paul Belchetz, and we approached several other thyroid specialists: Michael Sheppard, Michael Tunbridge and Professor Sir Dillwyn Williams. These endocrinologists alongside myself were to form the first Board of Trustees, with Sir Richard Bayloss as Chair.

We held our first meeting in Newcastle in July 1991, following a meeting to celebrate the centenary of George Murray’s discovery of thyroid extract. We had a name for the charity, we had a logo designed (which we still use) thanks to a graphic designer, Des O’Hara, who I worked with, and we had our first funds.

Michael Tunbridge kindly donated £1,000 - the profits from the George Murray meeting - to the newly formed British Thyroid Foundation. We set our objectives: awareness-raising, support and information, establishing local groups, and raising funds for research; and prepared the paperwork needed to register with the Charity Commission. The trust deed shows we paid the grand sum of 50p in order to register the charity!

Our first action was to start to prepare the patient literature, helped by a wide range of thyroid specialists.

The BTF was granted charitable status in October 1991. Unfortunately my father was diagnosed with terminal cancer in the summer and died just two weeks before that. I often think about how my dad inspired me. It’s sad he wasn’t here to see it all develop.

We launched the BTF at the British Endocrine Societies (BES) meeting in Harrogate in March 1992. Equipped with a basic display board (card and Letraset!) I made my way to Harrogate and announced the launch of the BTF to an auditorium of endocrinologists. Paul Belchetz and I then had an interview on BBC Radio Leeds, and later that evening the phone (my home phone as we had no office back then!) started to ring. And the phone hasn’t stopped ringing since that day.

The spare room became the main hub of activity for the next five years. The BTF work necessarily had to take place in the evening, when I got home from work and had put the children to bed: answering queries, sending out information, hatching future plans, such as should we have local groups, what about telephone support further afield…

Continued on page 10
Our first newsletter, four pages in black ink on white paper, was sent out to a few hundred people in summer 1992. I borrowed the photocopier at work to do this, and got some friends together to stuff the envelopes. There were other tasks and matters to comply with too, such as setting up bank accounts, phone lines, fulfilling account procedures, reports to the Charity Commission, etc. which were quite time-consuming, although looking back they were far simpler then than they are now!

Thankfully, before too long, people came forward to offer their help - local people in the first instance. Thanks to the first volunteers - Celia Hamilton (still a BTF member), and Betty Nevens, we were able to provide information to enquirers. And of course, Alan Menzies, who was with the BTF as Treasurer from 1992 until last year, and took a keen interest not only in dealing with the accounts, but also in the work we did. Later we were joined by others. Their help was vital.

In 1993 I started to make contact with people who were interested in setting up a local group and later that year we met, the result being that the first 20 (!) BTF local groups were established.

In 1995 we managed to acquire a room in a hospital in Leeds, which became the BTF HQ, although I still worked from the spare room when I got home from work. We now had two employees and volunteers who worked from the office.

By 2001 the BTF was growing, and it came time to make a decision as my role as National Coordinator could no longer function on a voluntary basis. I was invited by the Trustees to take on the role of Director so I resigned from my job in Leeds and became an employee of the BTF. In 2002 we moved to bigger premises in Harrogate. By then we had three employees, including myself. In 2008 we took on more office space, employees and volunteers.

The needs of thyroid patients were evident so we set up a structure to address their concerns: a website, groups to head up projects and campaigns, and a regular review of our information.

We have been working formally with the British Thyroid Association since the 1990s which has meant that we could listen to what patients wanted and convey their concerns to thyroid specialists.

I have been so lucky in having such a supportive family - not only did they give me moral support on so many occasions, and forgive me for not always being there on family occasions, and for late mealtimes and late nights, but they have helped in so many
ways, volunteering at the office (as have other employees’ children), helping to set up at exhibitions/conferences, helping to proof read the newsletter (Eleanor, my daughter), website (Matthew, my son, provided the graphics), but particularly Bryan, my husband, who has been involved from the very beginning.

The BTF needed to grow rapidly to meet patients’ needs and it required a sound IT structure. The opportunity came with the new larger offices. Bryan set up the database, has done all the programming, and takes care of all our IT needs, including training us and producing the newsletter data so that people can receive their newsletter! He has set up a secure computer network, and is there to answer questions from all the office staff and troubleshoot when we have problems. I really could not have done it without him… and he saves us a fortune!

What are the biggest changes that have taken place in the past 21 years?

The changes over the past 21 years have been enormous. No longer do we expect patients to be simply on the receiving end of healthcare; many want to be actively involved not only in decisions about their own health care but also in research, in discussions (to shape the future of the NHS, for instance), giving feedback on guidelines, and fundraising.

Patients question their doctors more readily, and the BTF endeavours to give them the tools to be able to ask the questions that will help them receive reliable answers.

Dialogues between medical/health professionals and patients take place more frequently, and patients are more aware of the bigger picture, how they can get involved, and the shared responsibility for healthcare.

What are you most proud of?

That the BTF is still going strong! Despite some hiccups and challenges (and we do know we have lots more to do to help people), we have achieved a lot in 21 years.

And that we have helped so many people over the years - we receive lovely letters and comments from people who tell us we have made a difference.

All the fantastic people I have met over the years who have believed in the BTF, who have got involved, joined the team, and helped to make the BTF stronger, bringing their skills and energy to the charity. I feel very well supported.

And feeling that I have two great families - the one at home, and the one at work!

BTF AT BES 2013

BTF returns to its origins at BES 2013

In March the BTF was invited to exhibit at the Society for Endocrinology’s BES Annual Conference along with other patient support organisations. The BTF shared a stand with the Thyroid Eye Disease Charitable Trust (TEDot).

It was poignant that this year’s meeting was in Harrogate as it was here that the BTF was launched 21 years ago.

A highlight of this year’s BES conference was the ‘Meet the Expert’ Session where Dr Tim Cheetham gave a talk about ‘Challenges in managing hyperthyroidism in young people’. The session was supported by the BTF who gave out packs of information and a copy of the BTF’s DVD on thyroid disorders in children to the people attending the talk.

Dr Cheetham gave a lucid overview of the current challenges facing doctors and their patients in treating hyperthyroidism in young people and about weighing up the options between surgery and treatment with radioactive iodine. This was an extremely well-attended talk and prompted a lively question and answer session at the end.

21st anniversary reception at the BES

During the BES conference the BTF hosted a reception at the Holiday Inn adjacent to the Conference Centre, which was attended by medics, past and present, Trustees, volunteers and others who have helped the BTF over the years.

Among the guests were Dr Michael Tunbridge, a BTF Patron and former Trustee, and Dr Paul Belchetz, also a former Trustee, each of whom played a key role in establishing the BTF.

Representatives of some of the patient support organisations we work with were also present, as well as Paul Keen, designer of BTF News.

John Lazarus, a former Trustee of the BTF and past President of the BTA, who still works closely with the BTF on the pregnancy and iodine projects, gave a short address to congratulate Janis and the BTF on this milestone achievement.
MY STORY

Meet Bridget O’Connor, BTF Local Coordinator

Bridget runs the BTF Nottinghamshire and Derby group and is also a telephone contact for the BTF and Hypoparathyroidism (HPTH) UK as well as fundraising for both organisations.

In 2007 she was diagnosed with Graves’ disease and when the treatment with antithyroid drugs failed to have an effect she had surgery - an experience she has found life-changing since, as she says, ‘I went into hospital with one endocrine condition and came out with another’, but she has been able to carry on working as a health and family support worker at Sure Start, and still enjoys life. She writes:

I was diagnosed with a thyroid disorder six years ago. I was mega-stressed at the time because my mother-in-law was dying of terminal cancer, which rips any family apart, but by February 2007 I was shaking inwardly and out, sweating, anxious, and continually tired, and had lost three stone in two months.

One day I was trying to get coffee granules into a cup and was shaking so much that I decided to call my GP. He took some blood tests and called me a week later to explain that my thyroid level was nearly off the scale at 60. He explained I had Graves’ disease (over-active thyroid). I was referred to an endocrinologist. I had atrial fibrillation and was given beta blockers, then had ultrasound scan, radioactive iodine uptake scan with gamma camera, and fine needle aspiration.

I was put on carbimazole and I had monthly blood tests to check my white cell count, but eleven months later I still had many of the same symptoms and was recommended to have the thyroid removed.

Surgery followed. I was told about the risks of bleeding, vocal cord damage, and infection but I don’t remember being told about the risk of removing or damaging my parathyroids. It just said ‘ca risk’ on my consent form...

I first realised there was something wrong the morning after the operation. I had tingling, tetany, frozen vision that went to black and white, and I felt like a machine that was grinding slower and slower and was going to stop, I couldn’t lift my head to drink or move my tongue and had to use little sponges on sticks to wet my lips.

I found out after I was discharged with medication and got home that I now had hypocalcaemia (low blood calcium). Later I learned that I had hypoparathyroidism: my parathyroids - the four little glands behind the thyroid that control calcium levels - had been removed or damaged.

I was unwell for a long time after surgery and my endocrinologist gave me T3 as well as T4 to see if that would help, but this had little or no effect and was stopped. My hypothyroidism is now managed well on levothyroxine.

My parathyroids didn’t recover after surgery and I now have ‘brittle’ hypoparathyroidism which means I have unexplained dips and highs of calcium levels. I take alfalcacidol and copious amounts of calcium daily and my eyes are dry and I use gel tears every day. I fluctuate between high and low calcium levels and once I had a spell of my kidneys not working properly when my calcium levels were too high. I can now recognise the signs of low calcium. I keep logs of all my blood test results and keep a diary of symptoms when I feel ill for a period of time and see an endocrinologist every three to four months. I am very lucky and have a good GP and endocrinologist who look after me.

My experience has been life-changing. I went into hospital with one endocrine condition and came out with another. I wear a special medical talisman around my neck at all times in case I ever have an accident so people know I might not survive without my medication and supplements.

It hasn’t been an easy journey, but I have never once felt sorry for myself. My life has changed immeasurably since I was first diagnosed, but I’ve managed to carry on working and still enjoy life.

I have found the support of the BTF and HPTH UK invaluable both pre- and post-op. So I now volunteer for both organisations.

There were no support groups in my area so I started a local support group for thyroid and parathyroid disorders which has been meeting regularly for four years.

I work closely with the Endocrinology Department at the King’s Mill Hospital, Nottingham which supports us by organising and promoting thyroid/parathyroid awareness evenings once a year at two different sites. Around 550 people have already attended! Last year the hospital invited the group to participate in internet training for the expert patient session about finding reliable and safe information on the internet.

I also run a telephone helpline for the BTF and Hypoparathyroidism (HPTH) UK. I have had telephone helpline training kindly provided by the British Society for Endocrinology and HPTH UK.

I raise funds for both the BTF and HPTH UK and regularly hold raffles and tombolas. I’ve also organised a hoe down and a summer fayre with the help of my lovely work colleagues at Sure Start.

But my most special fundraising effort has been my little book Hisham’s Envelope which I wrote for children who may have a medical condition and may need blood tests and visits to the doctor or to hospital clinics. I dedicated the book to my endocrinologist who was my saving grace after surgery and at the endocrine clinics, all the proceeds from my little book and fundraising efforts are split 50-50 between the BTF and HPTH UK.

We need better awareness of thyroid and parathyroid conditions both in the general public and within the medical establishment so I recommend people to ask for a referral to see a specialist and get support from someone who has been through it so you can understand how a diagnosis doesn’t have to spell the end at all.

For anyone facing surgery I am always honest and point out that my experiences are personal to me, to choose a surgeon wisely and choose one who is experienced in doing thyroid surgery. It is all about giving people reliable safe information for them to make their own decision.

If you would like to know more about hypoparathyroidism and hypocalcaemia visit the website of our sister organisation HPTH UK at www.hpth.org.uk. HPTH UK also distributes a leaflet about hypoparathyroidism produced in conjunction with the Bone and Mineral Special Interest Group of the Society for Endocrinology.

‘I am proud to be a BTF patron and to support the fabulous work that the charity does to help and guide anyone with a thyroid disorder.’

(Melissa Porter, TV presenter)
MEDICINES UPDATE

Eltroxin tablets ‘temporarily unavailable’

Mercury Pharmaceuticals Ltd (formerly Goldshield) has been supplying levothyroxine as both the branded (Eltroxin) and unbranded (levothyroxine) tablets.

The Commission on Human Medicines has made a number of recommendations which are supported by the MHRA. One particularly noteworthy recommendation in view of the BTF’s campaign for longer prescription lengths (see BTF News 68 and 69, 2009) is that:

‘Levothyroxine should be prescribed and dispensed in quantities covering three months supply, where appropriate, in order to address issues of continuity of supply and also to improve convenience to patients.’

Source


Is there a link between hypothyroidism and cyclical breast pain?

AG writes: I have suffered with cyclical mastalgia [cyclical breast pain - Ed] for about 12 years but I have noticed that since being diagnosed with hypothyroidism four years ago my symptoms now last all month, even throughout my period, and it has become far more painful. My GP has tried me on the mini pill and hormone treatments to stop my periods but neither helped. I have also tried the traditional evening primrose oil, starflower oil and Angus castus. Again no change.

Is there a link to hypothyroidism and worsening hormonal symptoms? Is there anything I can do/take to ease the pain/tenderness?

Our medical advisor replies: Studies that have been published on this subject have tended to show an improvement of mastalgia symptoms in about a quarter of women following commencement of levothyroxine for hypothyroidism.

You appear to have tried the usual recommendations. However, it would be

Continued on page 14
Can patients with thyroid eye disease be treated with RAI?

PM writes: I have been hyperthyroid for three and a half years now and have been on 20mg Carbimazole for this entire time. I have mild thyroid eye disease and my recent thyroid function is normal with a free T4 of 18.5 and TSH of 1.31.

I have been discussing long-term plans with my specialist and he has recommended surgery and I have an appointment with a surgeon soon, however I would like to ask whether radioactive iodine (RAI) could be an option for me. My specialist had always said no because of my eye disease. However, reading the BTF leaflet it seems that this is not necessarily contraindicative.

Our medical advisor replies: Current guidance now states that patients with thyroid eye disease can have RAI safely. A course of steroids may be given to reduce the chance of a flare-up of the eyes. If the eye disease is burnt out (as might be the case if the disease has been present for more than three years) treatment can be given without steroids as long as hypothyroidism is avoided. An ophthalmology opinion may be necessary if it is unclear whether the eye disease is burnt out.

For more information see the consensus statement by EUGOGO, section on Management of Hyperthyroidism in Patients with Graves’ Orbitopathy (Thyroid Eye Disease): http://bit.ly/11OnENM.

Reference

Can Graves’ disease affect growth?

CL asks: I was wondering if you had any information about growth problems in teenagers with hyperthyroid disease? My daughter is 14 and was diagnosed with hyperthyroid disease six months ago. She has been on Carbimazole since the diagnosis. We are concerned that she hasn’t grown at all in height for over a year now. She is 5ft 1in and is feeling very small compared with her peers.

Our medical advisor states: The age at which growth stops varies considerably and it is therefore possible that your daughter is close to/at final height now. The fact that she hasn’t grown for a year makes me suspect that there is little growth potential remaining.

Height is linked to parental size and your paediatrician should be able to tell you whether 5ft 1in is in the expected range based on the height of you both (mum and dad).

Growth problems are reported in hyperthyroidism. It can tend to make younger children taller but it is also reported to be associated with a tendency to be a bit smaller as well in some circumstances. If your daughter was hyperthyroid for a long time before the diagnosis was made then it is possible that her growth has been affected to some extent.

Unfortunately at this stage there will be very little (if anything) that can make your child taller if she has progressed through puberty and if the growth plates in the long bones have turned from cartilage to bone.

Thyroid and IVF

PT asks: My wife is trying to get pregnant with IVF. She has an under-active thyroid and a private referral from her GP to see an endocrinologist. Could you recommend a consultant endocrinologist in London that specialises in fertility?

Our medical advisor replies: Most endocrinologists who see patients with thyroid disorders will be well placed to advise and manage your wife’s condition in the setting of IVF. She can be reassured that this is a situation that thyroidologists will be familiar with.

Welcome to our new local support group coordinators: Mary Newton (Cambridge), John Challis (Brighton) and Julia Charlton (Newcastle).

Birmingham

NEXT MEETING: Saturday 16 November 2013 2pm to 4pm at Yardley Baptist Church, Rowlands Road, South Yardley, Birmingham, B26 1AT

Professor John Watkinson - Consultant ENT and Head & Neck surgeon including thyroid (cancer), Queen Elizabeth Hospital Birmingham will endeavour to answer all your questions about thyroid related surgery including thyroid cancer.

CONTACT: Janet Tel: 0121 628 7435 janetdmp@gmail.com

Brighton

NEXT MEETING: See BTF website for details.

CONTACT: John email: beedingrectory@outlook.com or call 01903 810265

Cambridge

NEXT MEETING: Saturday 13 July 2013 10.30am to 1pm at Newnham College, Cambridge CB3 9DF.

Speakers will be Professor Krishna Chatterjee, Professor of Endocrinology, University of Cambridge, Dr Diana Wood, Consultant in Endocrinology, Addenbrooke’s Hospital and Dr Carla Moran, Senior Research Fellow, University of Cambridge and BTF Research Award winner 2010.
Coventry

NEXT MEETING: 7.30pm on the second Wednesday of the month at the Albany Club, Earlsdon Street, Coventry CV5 6EG. See BTF website for further details.

CONTACT: Colin Tel: 07973 861225

Edinburgh

NEXT MEETING: 7.15pm to 8.30pm on the last Tuesday of the month except for school holidays at Liberton High School, Gilmerton Road, Edinburgh, EH17 7PT. The meeting is a ‘drop-in session’ and anyone is welcome to discuss their particular thyroid condition and to get advice and support. See BTF website for further details.

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

Leeds (Wharfedale)

NEXT MEETING: A meeting with a speaker in endocrinology is planned for June/July 2013. See BTF website for further details.

CONTACT: Caroline Tel: 0113 288 6393

London

NEXT MEETING: Saturday 7 September 2013 10am to 1pm at The Atrium, Royal Free Hospital, Pond Street, London, NW3 2QG. For directions and details of public transport visit www.royalfree.nhs.uk.

Mr Fausto Palazzo, MS FRCS(Gen), Consultant Endocrine Surgeon at Hammersmith & Charing Cross Hospitals and Honorary Senior Lecturer at Imperial College, London, will give a talk and answer questions on any aspect of thyroid disease.

DONATION: Suggested minimum £2.

CONTACT: Lorraine Tel: 01843 579 793 or email lorrainewilliams@btf-thyroid.org www.thyroid-hope.blogspot.com

Milton Keynes

NEXT MEETING: Saturday 8 June 2013 10.30am to 1pm at The Pavilion, Open University, Milton Keynes, MK7 6AA.

If you are interested in setting up a local support group in your area please call the BTF office on 01423 709707 or email e.clegg@btf-thyroid.org.

Dr Kristien Boelaert MRC Senior Clinical Lecturer and Consultant Endocrinologist, Queen Elizabeth Hospital Birmingham, will give a presentation entitled ‘Under-active Thyroid - The diagnosis and management of primary hypothyroidism.’

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.

21st anniversary thanks

A big thank you to Wilma Beckett and the Milton Keynes Branch of BTF for the lovely bunch of flowers to mark the BTF’s 21st anniversary.

Newcastle

NEXT MEETING: Saturday 13 July 2013 from 10.30am to 1pm at Newcastle Central Library, 33 New Bridge Street West, Newcastle upon Tyne (five minutes’ walk from Monument Metro).

The meeting will be on ‘Discovery and empowerment: Discover what you want from a thyroid patient support group and through information feel empowered’.

CONTACT: Judith on 07981 318198 or email Julia. julia.charlton@northumbria.ac.uk to book a place

Notts/Derby

NEXT MEETING: Monday 2 September 2013 at 7pm at The Staff of Life public house, West End, Sutton-in-Ashfield, Notts, NG17 1FB. See BTF website for further details.

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

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:
Claire Balding
Lord Jamie Borwick
Jenny Pitman OBE
Melissa Porter BA (Hons)
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Gay Search
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FRCPCH
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FRCS FRQophth
Dr M Strachan MD FRCP (Edin)
Mrs Judith Taylor BA (Hons) (Chair)
Mrs Eleanor Temple LLB (Hons)
Barrister at Law
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 MBBS PhD FRCP - 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.
Hypoparathyroidism (HPTH) UK

http://www.butterfly.org.uk

http://www.thyroidsupportwales.co.uk

Thyroid Cancer Support Group Wales

HPTH Helplines 01342 316315 (South) and 01623 750330 (North)

Cancer52

AMEND

In the event of a complaint, please address your correspondence to ʻThe Chair of Trusteesʼ.

ALL ENQUIRIES TO: The British Thyroid Foundation, 2nd floor, 3 Devonshire Place, Harrogate, North Yorkshire HG1 4AA.

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 Number</th>
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<tbody>
<tr>
<td>Carole (FC,CS,RAI)</td>
<td>01204 853557</td>
</tr>
<tr>
<td>Dave (PC,CS,RAI)</td>
<td>07939 236313</td>
</tr>
<tr>
<td>Jackie (PC,CS)</td>
<td>01344 621836</td>
</tr>
<tr>
<td>Gay (G,TS)</td>
<td>020 8735 9966</td>
</tr>
<tr>
<td>Nia (U)</td>
<td>01942 819195</td>
</tr>
<tr>
<td>Karen (U)</td>
<td>01628 529212</td>
</tr>
<tr>
<td>Wilma (U)</td>
<td>01592 754688</td>
</tr>
<tr>
<td>Angela (U)</td>
<td>01943 873427</td>
</tr>
<tr>
<td>Angela (U)</td>
<td>01943 873427</td>
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</tbody>
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KEY

- Afternoons only
- 2 to 7pm weekdays only
- 10am to 12 noon weekdays
- After 6pm weekdays and anytime weekends
- Email only

<table>
<thead>
<tr>
<th>Ch</th>
<th>Thyroid disorders in children</th>
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<tbody>
<tr>
<td>C</td>
<td>Cancer of the thyroid</td>
</tr>
<tr>
<td>FC</td>
<td>Follicular cancer of the thyroid</td>
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<tr>
<td>PC</td>
<td>Papillary cancer of the thyroid</td>
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<tr>
<td>HCN</td>
<td>Hürthle Cell Neoplasms</td>
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<tr>
<td>CS</td>
<td>Thyroid cancer surgery</td>
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<tr>
<td>RAI</td>
<td>Radioactive iodine (I-131) ablation</td>
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<td>G</td>
<td>Goitre</td>
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<tr>
<td>TS</td>
<td>Thyroid Surgery (non-cancer)</td>
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<td>U</td>
<td>Under-active thyroid</td>
</tr>
<tr>
<td>ITSH</td>
<td>Isolated TSH deficiency</td>
</tr>
<tr>
<td>O</td>
<td>Over-active thyroid</td>
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<tr>
<td>GR</td>
<td>Graves' disease</td>
</tr>
<tr>
<td>RI</td>
<td>Radioactive iodine treatment for an over-active thyroid</td>
</tr>
<tr>
<td>TED</td>
<td>Thyroid eye disease</td>
</tr>
<tr>
<td>PH</td>
<td>Post-operative hypoparathyroidism</td>
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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

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<tr>
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<tr>
<td>Brighton John (U)</td>
<td>01903 810265</td>
</tr>
<tr>
<td>Birmingham Janet (PC,CS,RAI,PH)</td>
<td>0121 6287435</td>
</tr>
<tr>
<td>Cambridge Mary (O,RI,U)</td>
<td>01223 290263</td>
</tr>
<tr>
<td><a href="mailto:butterflyecho@hotmail.com">butterflyecho@hotmail.com</a></td>
<td></td>
</tr>
<tr>
<td>Coventry Colin (O,RLU)</td>
<td>02476 711577</td>
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<tr>
<td>Edinburgh Margaret (PC)</td>
<td>0131 6647223</td>
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<tr>
<td>Leeds (Wharfedale)</td>
<td>Caroline (O,U) 0113 2886393</td>
</tr>
<tr>
<td>London (U)</td>
<td>01843 579793</td>
</tr>
<tr>
<td><a href="mailto:LorraineWilliams@btf-thyroid.org">LorraineWilliams@btf-thyroid.org</a></td>
<td><a href="http://www.thyroid-hope.blogspot.com">www.thyroid-hope.blogspot.com</a></td>
</tr>
<tr>
<td>Milton Keynes Wilma (U)</td>
<td>01908 330290</td>
</tr>
<tr>
<td>Newquay upon Tyne &amp; North Tyneside Julia (U)</td>
<td><a href="mailto:julia.charlton@northumbria.ac.uk">julia.charlton@northumbria.ac.uk</a></td>
</tr>
<tr>
<td>Notts/Derby Bridget (GR,TS,U,PH)</td>
<td>01623 750330</td>
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http://www.thyroidsupportwales.co.uk

Butterfly Thyroid Cancer Trust Tel: 01207 545469
http://www.butterfly.org.uk

Cancer52 http://www.cancer52.org.uk

OUR PARTNER ORGANISATIONS

Thyroid Eye Disease Charitable Trust: Tel: 0844 8008133
http://www.tedct.co.uk

British Thyroid Association http://www.british-thyroid-association.org

British Association of Endocrine and Thyroid Surgeons http://www.baets.org.uk

Sense about Science http://www.senseaboutscience.org.uk

BRITISH THYROID FOUNDATION DETAILS

ALL ENQUIRIES TO: The British Thyroid Foundation, 2nd floor, 3 Devonshire Place, Harrogate, North Yorkshire HG1 4AA.

Tel: 01423 709707 or 01423 709448 website: http://www.btf-thyroid.org. Office enquiry line open: Mon to Thurs, 10am - 2pm.

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

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Webmaster: Claire Skafie

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Development Officer: Julia Priestley

Editor: Judith Taylor email editor@btf-thyroid.org

Assistant Editor: Nikki Brady email n.brady@btf-thyroid.org

Medical Editor: Dr P Perros

Head Office Volunteers: Jan Ainscough, Jennifer Linley, Helen Dawson, Angela Hammond, Vivienne Rivis, Nikki Brady, David Fortune

Design and artwork for BTF News: Keen Graphics 01423 563888

Next issue of BTF News: September 2013. Letters and articles should be sent to the Editor, BTF News by 26 July 2013. News from local groups should be sent in to Liz Clegg; e.clegg@btf-thyroid.org to arrive by 8 August 2013.

For online donations please visit http://www.justgiving.com/btf/donate or text our unique code - THYR01 - and the amount you would like to donate to 70070.

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CURRENT MEMBERSHIP RATES

By cheque

<table>
<thead>
<tr>
<th>Members living in the UK</th>
<th>Full: £20 per year</th>
<th>Concession: £10 per year</th>
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<td>Members living overseas</td>
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<td>£25 Europe</td>
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<td>£35 Outside Europe</td>
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By standing order

<table>
<thead>
<tr>
<th>Members living in the UK</th>
<th>Full: £17 per year</th>
<th>Concession: £8.50 per year</th>
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<tr>
<td>Members living overseas</td>
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Lifetime membership £200 by cheque

Concession: unwaged, senior citizen, under-18s and students in full-time education

Please help us by ensuring that you pay the correct subscription.

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